

ACTION IN CHRONIC FATIGUE SYNDROME: AN ENACTIVE PSYCHO-
PHENOMENOLOGICAL AND SEMIOTIC ANALYSIS OF THIRTY NEW ZEALAND
WOMEN'S EXPERIENCES OF SUFFERING AND RECOVERY

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Abstract

This research into Chronic Fatigue Syndrome (CFS) presents the results of 60 first-person psycho-phenomenological interviews with 30 New Zealand women. The participants were recruited from the Canterbury and Wellington regions, 10 had recovered. Taking a non-dual, non-reductive embodied approach, the phenomenological data was analysed semiotically, using a graph-theoretical cluster analysis to elucidate the large number of resulting categories, and interpreted through the enactive approach to cognitive science.

The initial result of the analysis is a comprehensive exploration of the experience of CFS which develops subject-specific categories of experience and explores the relation of the illness to universal categories of experience, including self, 'energy', action, and being-able-to-do.

Transformations of the self surrounding being-able-to-do and not-being-able-to-do were shown to elucidate the illness process.

It is proposed that the concept 'energy' in the participants' discourse is equivalent to the Mahayana Buddhist concept of 'contact'. This characterises CFS as a breakdown of contact. Narrative content from the recovered interviewees reflects a reestablishment of contact.

The hypothesis that CFS is a disorder of action is investigated in detail.

A general model for the phenomenology and functional architecture of action is proposed. This model is a recursive loop involving felt meaning, contact, action, and perception and appears to be phenomenologically supported.

It is proposed that the CFS illness process is a dynamical decompensation of the subject's action loop caused by a breakdown in the process of contact.

On this basis, a new interpretation of neurological findings in relation to CFS becomes possible. A neurological phenomenon that correlates with the illness and involves a brain region that has a similar structure to the action model's recursive loop is identified in previous research results and compared with the action model and the results of this research. This correspondence may identify the brain regions involved in the illness process, which may provide an objective diagnostic test for the condition and approaches to treatment.

The implications of this model for cognitive science and CFS should be investigated through neurophenomenological research since the model stands to shed considerable light on the nature of consciousness, contact and agency.

Phenomenologically based treatments are proposed, along with suggestions for future research on CFS. The research may clarify the diagnostic criteria for CFS and guide management and treatment programmes, particularly multidimensional and interdisciplinary approaches.

Category theory is proposed as a foundation for a mathematisation of phenomenology.

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1. Introduction

1.1 Contributions from the Literature Review

Presented in chapter 2, my review of the literature on Chronic Fatigue Syndrome (CFS) from the disciplines of medicine, psychology, psychiatry, psychotherapy and sociology revealed three common themes: a lack of clear diagnostic criteria, a propensity to analyse this chronic psychosomatic syndrome through disciplinary boundaries that assume a dichotomy of mind from body and a lack of phenomenological understanding of the condition. The lack of uncontroversial and well-established diagnostic criteria systematically undermines the progress of research.

The literature reviewed does suggest that CFS cannot simply be considered a psychiatric or psychological disorder. The biomedical literature shows some promise in establishing specific somatic aspects of the disorder, in particular, that certain brain regions are in some way implicated in the condition.

Where the medical and psychiatric literature tends to reduce the problem of CFS to the somatic, psychology, psychosomatic medicine and psychotherapy tend to reduce CFS to the psyche. The pervasive assumption is that the condition can or should be ascribed to either a somatic or psychogenic etiology and that when this debate is settled it will resolve much of the controversy that surrounds the condition. That it is possible to reduce this syndrome to either somatogenic or psychogenic origin I believe is an open question. Existing research does not attend to observing illness processes.

Given the evidence, I suggest a comprehensive phenomenological exploration and investigation of ‘what the experience of CFS is’ that does not assume a dichotomy of mind from body stands to more accurately characterise the condition. Such an approach may clarify the diagnostic criteria and contribute towards presently lacking management and treatment approaches to CFS.

1.2 Research Objectives

To begin to address these lacunae the present research aims to provide a comprehensive phenomenological examination of thirty New Zealand women’s experiences of CFS, one that is open to a hermeneutic process of exchange with third-person research, and, therefore, allows for interdisciplinary engagement. Such a comprehensive examination will need to attend to the different processes of the illness experience, including recovery, stands to contribute to a clarification of the diagnostic criteria for CFS and to potentially guide treatment and management approaches, particularly those which are multidimensional or multidisciplinary. The

present research aims to attend to the ‘psychosomatic’ complexity of CFS in a manner that is not reductive. Rather, the research will need to enlist a conceptual framework for the interdependence of psyche and soma that does not limit understanding of this exchange to pathology.

1.3 The Problematic

To consider the phenomenality of CFS is to consider a form of suffering, an illness process and a psychosomatic phenomenon. These three themes are discussed in chapter 3.

To understand suffering and its alleviation the research enlists, from the Mahayana Buddhist wisdom tradition, the Prasangika-Madhyamika philosophical approach to the definition of suffering. This approach considers practices of exploration and interpretation crucial to the definition and alleviation of suffering. Phase One of this research is an exploration of CFS as a form of suffering while Phases Two and Three present interpretations.

Investigating what kind of experience CFS is involves asking what processes make up this chronic experience and what the meanings of those processes are. What stands to provide crucial insight into the nature of the illness process and its treatment (potentially the alleviation of this suffering) is the process of recover-ing. In effect, asking what kind of experiential process CFS is entails the additional question: what is the experience of recovering from CFS? In other words, how does the process end, what occurs next, and what do these elucidate about the illness process? Also, the examination of recovery potentially directly contributes to the development of a treatment program by discovering what wellness and recovery entail for CFS sufferers.

It is often assumed that the body can only be interpreted with the mind and that the body does not offer a reciprocal interpretation and contribution to the mind. I argue that the bodily contribution to experience through the vehicles of meaning and language is a critical consideration in assessing psychosomatic phenomena. To overcome the mind-body dichotomy a non-dual embodied approach is necessary to both the exploration of the expression of CFS by sufferers and the conceptual interpretation of this expression. What is needed is an approach that acknowledges the role of the body in creating meaning, experience and language. In this way the body can inform the exploration and interpretation of the CFS experience. The principal conceptual tools this research enlists towards these ends are Gendlin’s theory of meaning (Gendlin 1962) and enactive cognitive science.

Aspects of the enactive approach to conscious experience that underpin the research are discussed in chapter 4. The research draws mainly on Torrance’s (2005) second enactive approach, particularly the enactive critique of Cartesian dualism and the middle way of mindful awareness. The demonstration of no-self, the aggregates, the ‘Wheel of Karma’, basic element

analysis, the mental factors, and the enactive ontologically fragile self are essential to the enactive analysis of the semiotic analysis of the phenomenal data. The demonstration of no-self also contributes towards the Prasangika definition of suffering employed in the research.

The methodology developed in chapters 5 and 6 is a synthesis of Gendlin's theory of the generation of meaning, enactive cognitive science, first-person psycho-phenomenological methods for the study of experience, Greimasian semiotics, and mathematical graph theoretic cluster analysis.

The application of the methodology is discussed in detail in chapter 7.

1.4 The Interviews

To capture the participants' experiences, psycho-phenomenological interviews were conducted with thirty women recruited equally from two of the main geographical areas of New Zealand: the Canterbury and Wellington regions. Participant subgroups attend to differences in the participants' experiences of health care facilities and support groups and to duration of illness, including recovery. Given the exploratory nature of Phase One of the research, I did not target a particular age, sexuality or ethnic group as this would assume these factors were relevant.

Interviews were conducted to achieve inter-participant and intra-participant (Depraz, Varela, and Vermersch 2003, p.94) saturation of narrative time (Rudrauf et al. 2003, p.52) first-person (Varela and Shear 1999a) phenomenal invariants. Participants were encouraged to be actively and collaboratively involved in the process of identifying and exploring phenomenal invariants. In this way, participants were part of the process of knowledge production. Given the stigma (Åsbring and Närvänen 2002) often involved with a diagnosis of CFS and the experiences of objectification and discrimination that many of the interviewees relate, this participation was particularly appropriate. Chapter 7 presents the research method.

Participants involved in the pilot study for this research related significant experiences of stigmatisation in social and medical settings. Pilot study participants reported becoming cautious about relating their experiences. An aim of the research was to establish a relationship of empathy with the participants so that they could feel at ease in sharing their experiences. The first-person method developed in this research allowed me, as the second-person researcher, to develop the relationship of empathy necessary for participants to speak freely of their experiences.

Illness is not a static process. Interviews conducted in the pilot study for this research suggested that the chronicity of CFS involves a progression of stages. Existing research does not demonstrate sensitivity to these contours of the illness process. Instead, the illness is treated as a flat experience. This approach does not capture the broader illness experience. The present

research is concerned with capturing as many of the aspects of the participants' illness experience as possible across the entire progression of the illness. Particular attention is paid to the process of recovery.

Ten of the research participants had recovered from CFS at the time of the interviews. These participants described both their illness experience and their recovery in detail. The research analysis pays close attention to the differences between the reports from the ill and recovered participants and reveals a significant number of phenomenal invariants that are unique to one or other of these subgroups. Although there is an increasing body of literature that attends to ways in which isolated aspects of CFS can be treated or managed, there is no consensus with respect to an adequate approach to providing comprehensive treatment or illness management, particularly for women. By examining the whole illness experience and, particularly, the experiences of women who have recovered from CFS, the research provides material that may contribute to the development of management and treatment programmes.

1.5 Thesis Structure

To address the research objectives the thesis is structured in three phases.

1.5.1 Phase One

The objective of the first phase of the research is to provide a comprehensive exploration of the participants' experience of CFS.

Whilst the research subject is asked to evoke and explicate experience, it is the researcher's role to conceptualise experience, to develop categories of experience and an understanding of the structure of an experience (Vermersch 2009). This is a hermeneutic process. Equally, as the categories and structure of the experience emerge, these will inform how the researcher guides the subject and may lead to the subject considering aspects of the experience that would, otherwise, not be addressed. Vermersch (2009) draws a distinction between two sets of descriptive categories in the analysis of experience: categories, or aspects, specific to the experience that is the subject (or topic) of a particular phenomenological investigation, and categories or aspects of experience universal to all lived experience.

These categories constitute the specific theoretical expertise of the researcher, and the purpose of his research. For each new subject of research, they must be invented and discerned; the first descriptions, the first questionings, are a matter of trial and error. It may be the aim of an initial research, beginning a new programme, to discover what are the stages, properties, and variants of the realisation of a material or intellectual task, of the consciousness of an internal state, of an egoic property (Vermersch 2009, p.46).

Phase One of this research is concerned with the investigation of those categories that are specific to the experience of CFS. This initial research program is necessarily exploratory and stands to inform third-person research by defining first-person variables that can give rise to operational third-person variables. Objective, third-person variables can only be derived if first-person experience is first studied.

The formalisation of the CFS experience that results from this initial exploration is presented in chapter 8. This formalisation involved the first level of semiotic analysis of the experience, which required an initial coding of the interview transcripts into nodes and the initial clustering and analysis of these nodes. What this formalisation of the experience suggested was that the role of the self and ‘energy’ in the discourse presented by the interviewees warranted further analysis with respect to action.

1.5.2 Phase Two

Phase Two of the research, presented in chapters 9, 10 and 11 excluding the analysis sections, concerns two universal descriptive categories of experience that were shown in Phase One to be fundamental to the experience of CFS: ‘energy’ and the self. Vermersch specifies three kinds of universal descriptive categories. The self and ‘energy’ are both examples of universal descriptive categories of the second kind: “the second takes into account the general components of the description of all lived experience, on the basis of the fact that all subjectivity will have cognitive, sensorial, thymic, corporeal and egoic aspects, in whatever way you wish to make this division as a matter of principle in order to remain coherent with your theoretical research framework” (2009, p.48). Phase Two of this thesis pursues exploring the hypothesis that these two universal descriptive categories of experience elucidate the structure of the experience of CFS. To investigate these universal categories of experience, a second semiotic analysis, guided by the results of the first semiotic analysis, was conducted.

The three objectives for Phase Two were established on the basis of the results of Phase One.

The Phase One semiotic analysis showed the centrality of the term ‘energy’ to the participants’ discourse and its connection to action through expressions of being-able-to-do or not-being-able-to-do. Investigating the relationship between the term ‘energy’ and action semiotically was the first objective of Phase Two. The meaning of this universal category ‘energy’ and its experiential function in the discourse needed to be discovered. This forms the second objective of Phase Two.

In the results of the semiotic analysis conducted in Phase One the connections between recovery and the ability-to-do and illness not-being-able-to-do, and the importance of

transformations to the self to the illness process, and recovery were observed. The third objective of Phase Two was, therefore, to investigate the self narratives present in the discourse and their relationship to action.

The contribution from ill and recovered participants to each of the original nodes established in the first coding process was assayed by number of extracts, number of words in extracts and the actual content examined. Nodes where the contributions were significantly different were identified. Examining in detail the contributions to each of the nodes from the ill and recovered participant subgroups showed that there were eleven nodes that contained content from only recovered participants and seven nodes that contained content from only ill participants.

Most of the eleven nodes that contained content from recovered interviewees alone were members of the recovery cluster (Figure 13). The self is of central importance to all twenty nodes in this cluster and the self was of central importance to all of the remaining nodes that showed a significant difference in contribution from ill and recovered participant subgroups. There were three clusters that did not contain significant data on the self: “energy”, “body” and “biomedicine”. The contents of all the nodes from the other clusters were recoded with a focus on the self.

The contents of the nodes from the Energy cluster were also recoded more finely.

The results of the second semiotic analysis provided a formalisation of ‘energy’ for the enactive analysis conducted in Phase Three. The semiotic analysis alone did not adequately explain the relationship between ‘energy’ and action or its experiential function. Six self narratives were identified in Phase Two, four narratives of illness and two of recovery. These convey the self transformations involved in the illness process. The semiotic analysis of these self narratives was largely adequate, however, further enactive analysis of these self narratives was also conducted in Phase Three. Phase Two completes the semiotic analyses conducted in the research.

1.5.3 Phase Three

Phase Three can be divided into three parts. Part One is the enactive analysis of the second semiotic analysis of Phase Two, and is presented in sections 9.9, 10.6 and 11.8, which are the analysis sections of those chapters. The second and third parts of Phase Three are developed in chapter 12 and do not involve direct reference to the interviews.

Part One

In Phase Three Part One, an enactive analysis was applied to the results of the second semiotic analysis presented in Phase Two. With respect to the four self narratives of illness

identified in the semiotic analysis, a lack of affect, proprioception, and an absence of self-awareness was identified through the enactive analysis. With respect to the two self narratives of recovery, a reassessing of doing, being, mind, body, thinking, feeling, affect, and world was identified. A strong feature of the recovery selves was the ability to choose new directions for the self, to be an ontologically fragile self.

It is proposed in the enactive analysis that ‘energy’ is functionally equivalent to the Mahayana Buddhist concept of ‘contact’. The ways in which contact breaks down in illness and is reestablished in recovery are explored.

Part Two

The objective of Phase Three Part Two is to investigate whether or not CFS is a disorder of action. Towards the construction of a model which describes the process of the generation of meaningful and viable action, Boyd’s OODA loop is reviewed in section 12.6. Connections between Boyd’s existing model of action and autopoiesis, operational closure, and Gendlin’s concept of felt meaning are drawn. In the next section, 12.7, a synthesis of concepts drawn from the enactive approach, Gendlin, and Boyd is used to develop a model for the process of the generation of meaningful and viable action. This model proposes a recursive loop involving felt meaning, contact, action, and perception. The action model proposed appears to be phenomenologically supported by the work of Gendlin and the findings of this research.

Given this new action model, a new interpretation of neurological findings in relation to CFS becomes possible. In section 12.8, a neurological phenomenon that correlates with the illness and involves a brain region that has a similar structure to the action model’s recursive loop is identified in previous research results and compared with the action model and the results of this research. If the action model and the correspondence between the action model and this neurological finding bears out in further research, this correspondence may identify the brain regions involved in the illness process. Potentially this provides an objective diagnostic test for the condition and a point from which to investigate neurological and biomedical approaches to treatment. The implications of this model for cognitive science should be investigated since the model stands to shed considerable light on the nature of consciousness. As an approach to future research concerning the relation between action, perception and agency, neurophenomenology is strongly suggested by the findings of the present research.

Phenomenologically based treatment suggestions are proposed in section 12.10. This section also mentions specific approaches to future research on CFS. A treatment approach to CFS will require an understanding of suffering. In section 12.9 it is suggested that the Prasangika definition of suffering is a suitable candidate for this task.

Part Three

Phase Three Part Three is a general reflection on the research process and the implications of the method employed for future research.

In section 12.2, I assess how enaction and first-person methods have contributed to the research and how this research may have extended or contributed to these research programmes. Section 12.3 considers the success of the method given the processes of verification internal to the research. From this perspective, it is concluded that the method employed has been successful. The success of the method in this research suggests that the methodology developed here should be pursued further. This conclusion is subject to the constraint that this method has not been independently verified. General suggestions for future research on CFS are presented in Section 12.4.

Varela (1997) and Lutz (2002a) call for a mathematisation of phenomenology. The experience of conducting this research has highlighted the efficacy of this suggestion. The question is, how should this be achieved? Category theory is proposed in section 12.5 as a foundation for a mathematisation of phenomenology.

2. Literature Review

2.1 Introduction

This review examines literature on CFS, and specifically on CFS and women, from the disciplines of medicine, psychiatry, psychosomatic medicine, psychology, psychotherapy and sociology.

Discussion of the nomenclature, diagnostic criteria, incidence, prevalence, etiology and epidemiology of CFS is presented in section 2.2. The controversy surrounding the diagnostic criteria and etiology of the syndrome is discussed.

Literature concerning the management and treatment of CFS is reviewed in section 2.3 and the lack of consistent approach to either is identified.

Medical and psychiatric literature is reviewed in section 2.4. Although this literature is very fragmented a small number of studies from neurology show some promise in establishing specific somatic aspects of the disorder, in particular that certain brain regions are in some way implicated in the condition.

Literature from the disciplines of psychosomatic medicine, psychology and psychotherapy is reviewed in section 2.5. Again, although fragmented, this literature does suggest that despite the significant co-morbidity between CFS and various psychiatric and psychological disorders CFS cannot simply be considered a psychiatric or psychological disorder. A critique of the tendency for research to psychologise CFS is offered and questions concerning the adequacy of somatisation as an explanatory device are raised.

In section 2.6 the available sociological research is considered. The paucity of this research, particularly with respect to women, is noted.

The New Zealand research context concerning CFS is presented in section 2.7. This context does not vary significantly from international findings.

Conclusions drawn from this review shape the aims of the research and reveal three common themes: the difficulties concerning diagnostic criteria, a propensity to analyse CFS through disciplinary boundaries that are underpinned by a dichotomy of mind from body and a lack of understanding of the phenomenology of CFS. From these themes, I argue, in section 2.8, that the present research needs to engage a phenomenological perspective that explores ‘what the experience of CFS is’, particularly for women sufferers. This phenomenological approach needs to be open to a hermeneutic process of exchange with third-person research and needs to enlist a conceptual framework that does not limit understanding of the exchange of mind and body to the pathological.

2.2 Nomenclature, Diagnostic Criteria, Incidence, Prevalence, Etiology and Epidemiology

Chronic Fatigue Syndrome (CFS), Postviral Fatigue Syndrome (PVFS), Myalgic Encephalomyelitis (ME), ‘Yuppie Flu’ and Tapanui Flu are some of the many names coined to identify what is a chronic and debilitating illness. Of unknown etiology (Richman and Jason 1998, p.24) this condition involves a plethora of both somatic and psychological symptoms that disrupt sufferers’ ability to function socially and productively.

Research examining CFS has been widely reviewed (Bock and Whelan 1993, p.187; Jason, Fennell, and Taylor 2003; Afari and Buchwald 2003; Breau and Ju ; Demitrack and Abbey 1996; Fischler 1999; Fry and Martin 1996; Garralda and Chalder 2005; Joyce, Hotopf, and Wessely 1997; Kerr et al. 2007; Manu, Lane, and Matthews 1992; Prins, Van der Meer, and Bleijenberg 2006; Richards 2000; Shephard 2005; Whiting et al. 2001). These reviews have been reviewed and no clear consensus about *any* aspect of the syndrome has emerged. Existing literature does, however, “perpetuate pre-existing disciplinary biases” (Joyce, Rabe-Hesketh, and Wessely 1998, p.266).

The 1994 Centre for Disease Control (CDC) diagnostic criteria for CFS is the most recent, comprehensive, and least contested definition of CFS:

- Clinically evaluated, unexplained, persistent or relapsing chronic fatigue lasting >6 months:
 - Of new or definite onset
 - Not the result of ongoing exertion
 - Not substantially alleviated by rest
 - Substantial reduction in previous levels of occupational, educational, social, or personal activities
 - Clinical Evaluation: History and Physical, Mental Status examination. Laboratory screening including CBC, ESR, LFTs, TP, albumin, globulin, CA, PO₄, glucose, BUN, CRE, electrolytes, TSH, urinalysis
- 4 symptoms concurrently present for >6 months
 - Sore throat
 - Tender cervical or axillary lymph nodes
 - Muscle pain
 - Multijoint pain
 - New headaches
 - Unrefreshing sleep
 - Postexertion malaise
- Exclusion criteria
 - Active, unresolved, or suspected disease likely to cause fatigue
 - Psychotic, melancholic or bipolar depression (but not complicated major depression)
 - Psychotic disorders
 - Dementia
 - Anorexia or bulimia nervosa
 - Alcohol or other substance misuse
 - Severe obesity (Fukuda et al. 1994)

This definition, and other criteria for the diagnosis of CFS, remain controversial (Eidelman 2003; Jason et al. 2003; Jason et al. 2001). These diagnostic criteria do not accurately represent the experience of the syndrome nor do they provide insight into the ways in which suffering from the condition disrupts sufferers' lives.

Jason, Leonard et al. (2001) argue that the discrepancy between the 1988 and 1994 CDC definitions results in the identification of different patient groups. The authors call for "operationally explicit, objective criteria and standardized interviews" and diagnostic procedures (Jason et al. 2001, p.342). King and Leonard comment that "future research should therefore focus on the development of an empirical case definition for CFS" (2005, p.105). How clarification of the diagnostic criteria for CFS might be reached is not proposed.

Kennedy, Abbot et al. claim to provide "evidence that the specificity of the CDC-1994 case definition of CFS could be improved to define more homogenous groups (or subgroups) of patients, especially for the purposes of clinical and laboratory research and directing patient management" (2004, p.99). How such improvements might be made is not discussed.

Although identifying subtypes or subgroups (Levine 1994; Calabrese, Davis, and Wilke 1994; DeLuca et al. 1997; Duprez et al. 2001; Janal, Ciccone, and Natelson 2006; Jason et al. ; Jason, Taylor et al. 2000; Leonard et al. 2003) is becoming an increasingly more common response to the controversy surrounding the CFS diagnosis, this approach does not appear to be producing any consensus. Approaches to identifying patient groups or clarifying diagnostic criteria do not ask, 'what kind of experience is this'. Instead, operating without a comprehensive understanding of the experience, this literature perpetuates widely varying existing disciplinary assumptions on 'what kind of experience this is'. These assumptions then determine the view of what to consider a subtype or subgroup of the CFS population.

Particular difficulty arises in distinguishing CFS from fibromyalgia (Fite and Kopala 2003; Sullivan, Smith, and Buchwald 2002; Zachrisson, Regland, Jahreskog, Kron et al. 2002), other fatigue syndromes (Whiteley et al. 2004) and functional somatic syndromes (Nimnuan, Rabe-Hesketh, and Wessely 2001).

The lack of adequate diagnostic criteria makes epidemiological studies difficult (Levine 1997) and consequently these studies shed little light on the disorder (Marshall 1999; Wessely 1998).

In a review of CFS, Shafran claims that "[r]eports of CFS have emerged from the United States, Canada, the United Kingdom, Australia, New Zealand, Israel, Spain and France" (1991, p.735) and there seems to be an increasing number of reports on CFS emerging from Korea (Kim, Shin, and Won 2005), Iceland (Líndal, Stefánsson, and Bergmann 2006, 2002), Japan

(Hashimoto et al. 1992; Minowa and Jiamo 1996; Ogawa, Toyama, and Matsumoto 1992), the United States of America (Buchwald et al. 1995), Russia (Artsimovich et al. 1994) and Czechoslovakia (Fucikova and Petanova 1993). Lloyd, Hickie et al. (1990) estimate the prevalence of CFS in a New South Wales (Australia) population to be 75.3 cases per 100,000 population. In most industrialized countries, CFS is reported to occur more often in institutional settings such as hospitals or as geographically specific epidemics (Murdoch 1989). Jason et al. (1998, p.92) report the prevalence of CFS amongst nurses to be 1,088 per 100,000. Determining how accurate accounts of the incidence or prevalence of CFS are is difficult due to the controversy surrounding diagnostic criteria. Solomon and Reeves (2004) argue that one consequence of the controversy surrounding the CFS diagnosis is that most cases of CFS go unrecognized. CFS is often not diagnosed or misdiagnosed as psychological morbidity or psychiatric disorder (Lawrie and Pelosi 1995).

CFS is often characterized as being a disorder that is principally due to psychosocial factors and is most prevalent in white, middle or upper class, well educated, previously successful and often perfectionist women (Abbey and Garfinkel 1991, 1991). Greenhalgh (1999), for instance, includes CFS in her description of a group of fashionable diagnoses. Her focus, however, is on exploring the phenomenon of sick building syndrome. Although such studies appear to be influential (they are widely cited and referred to) this characterisation of the syndrome is not consistently borne out and potentially leads to a psychologisation of the disorder. Barrows, for instance, states: “the CFIDS¹ population is incorrectly stereotyped as upper-middle class, white, female hypochondriacs; consequently symptoms often are belittled or ignored” and “this population has severe physical and cognitive disabilities that affect their professional, familial, and social lives” (Barrows 1995, p.327). Charlotte (2000) and Jason et al. (1999) show that in community-based studies of the Chicago area, CFS is most common among Latinos, African Americans and other ethnic minorities. The authors suggest that the incidence of CFS in ethnic minorities has been underrepresented. There are also an increasing number of studies on CFS in children and adolescents (Browne and Chalder 2006; Jordan and Robinson 2001; Colby 2007; Jordan et al. 1998; Jordan et al. 2000; Patel et al. 2003).

Much of the literature on CFS comments on the preponderance of women sufferers but few studies quantify this preponderance. Exceptionally, Reyes et al. (2003) claims the prevalence of CFS in women in Kansas is 373 cases per 100,000 population. This is approximately three times higher than for men in the same area. There have been few studies that examine the reasons for the female preponderance in diagnosis and no studies assessing whether this diagnostic pattern

¹Chronic Fatigue and Immune Deficiency Syndrome is one name for CFS.

accurately reflects the incidence of the diagnosis. Limited research has been conducted into issues that specifically concern women with CFS (Leonard et al. 2003; McCue 2004; Richman et al. 2000; Saltzstein et al. 1998; Schaefer 1995; Tevens 2004; Tuck and Wallace 2000). Consequently the apparently very different position of women in comparison to men and children with CFS goes largely unexamined and unexplained.

I suggest that the existing research concerning the nomenclature, diagnostic criteria, incidence, prevalence, etiology and epidemiology of CFS demonstrates a lack of understanding of the problem at hand, particularly for women. A comprehensive picture of ‘what this experience of suffering is’ could improve future research in these areas and the subsequent research that depends on clarity in these domains. Understanding what the experience of CFS is could reduce the controversy surrounding the syndrome. This would reduce the distress for sufferers that results from such controversy (Kleinman 1988).

2.3 Management and Treatment

Since the late 1990s there has been a substantial increase in literature concerned with the treatment of CFS. A plethora of approaches have been explored and reviewed (Bagnall et al. 2002; Chambers et al. 2006; McBride and McCluskey 1991; Whiting et al. 2001; Erdman 2003). Despite these efforts there remains no established approach to the management and treatment of the disorder. Evidence to suggest an efficacious pathway forwards is limited.

Cho, Hotopf et al. have reviewed the placebo effect across a broad range of treatment and intervention approaches to CFS and conclude that “in contrast with the initial hypothesis, the placebo response was substantially lower than the usual one third reported response in other medical conditions” (Cho, Hotopf, and Wessely 2005, p.305). The authors conclude: “at the clinical practice level, the finding of the overall low placebo response emphasizes the need to enhance the nonspecific effects in the current treatment of CFS. Contextual factors such as a collaborative therapeutic relationship should be maximized in the management of CFS” (Cho, Hotopf, and Wessely 2005, p.306). Little reason is given for this conclusion and it is not clear what this low placebo response reflects. Does this question the assumption that CFS is a form of attention seeking, for instance? Does it strengthen the argument for a somatic basis to the disorder? Answers to either of these questions are not straightforward.

A recent review, screening ten thousand articles proposing or discussing the treatment of CFS, and closely examining seventy studies, suggested that cognitive behavioural therapy (CBT) and graded exercise therapy (GET) appear to be the most promising approaches to treatment (Bagnall et al. 2007). An overarching conclusion of this report, however, is that the heterogeneity of the studies considered excluded meta-analysis and made evaluating

interventions difficult. The majority of studies concerned with the treatment of CFS consider the use of CBT. Second most common are studies of GET. It is likely, therefore, that these therapeutic approaches are overrepresented.

2.3.1 Cognitive Behavioral Therapy

Studies of the treatment of CFS with CBT in children, adolescents or adults show limited positive results (Deale, Chalder, and Wessely 1998; Bertagnolli and Morris 1997; Prins and Bleijenberg 1999; Raine, Haines, and Sensky 2003; Stulemeijer et al. 2005; Wessely 1999). CBT appears to promote better functioning and higher self-reported wellbeing. Which symptoms CBT alleviates, and to what extent, varies significantly across studies.

In my review, no studies of CBT claimed to alleviate somatic symptoms. Several studies suggested that the success of the CBT offered required highly skilled therapists and was largely due to the individualisation of the treatment (Bazelmans, Prins, and Bleijenberg 2006; Prins et al. 2001; Sharpe 1998). Burgess and Chalder (2001) demonstrate that CBT can be delivered by phone with some success. Consistently, Bazelmans, Prins et al. (2005) have shown that group CBT is less effective than individual CBT. Group CBT has been shown to reduce fatigue and increase functioning and sense of well-being (Saxty and Hansen 2005; Wittkowski, Toye, and Richards 2004).

One study has suggested that CBT can be improved when it is combined with biofeedback (Al-Hagggar, Al-Naggar, and Abdel-Salam 2006). This same study notes that the success of the treatment plan employed was closely related to thorough initial client evaluation and a tailored therapy plan.

The outcome of CBT is not affected by psychiatric co-morbidity, however, according to Prins, Bazelmans et al. (2002) the effectiveness of CBT is significantly reduced while patients are involved in financial disability claims with insurance companies.

It is difficult to determine why CBT has shown some success. These successes may only be partly due to the nature of the therapeutic intervention and reflect the fact that any intervention is perceived to have some merit. This could equally be said of exercise therapies.

2.3.2 Exercise and Related Therapies

There seems little consensus with respect to the use of exercise therapies in the treatment of CFS. Wallman, Morton et al. (2004) have compared the exercise capacity, exercise tolerance and ratings of perceived effort of CFS patients and controls matched by gender, age, height, body mass and habitual exercise level. The authors propose that reduced exercise tolerance in CFS subjects may be “attributed to avoidance behaviours associated with fear of relapse, as well as an

abnormal sense of effort” (Wallman et al. 2004, p.1687). They suggest that CFS may involve a degree of exercise phobia. In contrast, Gallagher, Coldrick et al. (2005) claim to show that CFS does not involve exercise phobia.

Several studies suggest the importance of attending to patients’ beliefs about exercise and, in particular, to their perception that exercise may exacerbate symptoms (Kop et al. 2005; Silver et al. 2002). A small number of studies suggest that exercise leads to an exacerbation of symptoms which results in CFS patients reducing their average level of activity and the length of the day they remain active (Bazelmans, Bleijenberg et al. 2005; Clapp et al. 1999; Ohashi and Yamamoto 2002; Sisto 1997). In contrast, several studies claim that exercise does not lead to symptom exacerbation but this research does not support its use in treatment programmes (Cook et al. 2005; Coutts, Weatherby, and Davie 2001; LaManca et al. 2001). Sisto, LaManca et al. (1996) also claim that exercise does not aggravate symptoms but may produce fatigue and decrease vigor. Tapp, Lamanca, et al. (1998) claim that exercise has positive outcomes on activity levels in CFS patients but requires activity compensation. Other research suggests that exercise can potentially promote physical reconditioning and positive perceptions of health without the exacerbation of symptoms (Pardaens et al. 2006; Powell, Nye, and Edwards 2001; Xiao et al. 1998).

Paul, Wood and McLaren (2001) report higher effort perception among CFS patients. Davey, Puri et al. (2001) claim that CFS patients have a slower performance time on motor tasks. Jammias, Steinberg et al. (2005) assert that CFS patients demonstrate alterations in muscle membrane excitability whilst Barrett, Woodrow et al. (1998) maintain that CFS patients do not demonstrate the levels of muscle fibre deconditioning that would be expected for their level of activity. There is divided opinion on whether immune system responses can explain CFS patients’ poor performance on exercise related tasks (Nijs et al. 2004; Nijs et al. 2005; Sisto et al. 1999; Snell et al. 2005).

Several authors are investigating pain in CFS sufferers (Meeus, Nijs, and De Meirleir 2006; Nijs and De Meirleir 2006; Nijs, Van de Velde, and De Meirleir 2005; Schmaling and DiClementi 1995; Nijs, Meeus, and De Meirleir 2006). On the basis of a preliminary study Nijs, Meeus et al. suggest that “physiotherapy, pacing self-management techniques, and pain neurophysiology education are indicated for the treatment of musculoskeletal pain in CFS patients” (2006, p.190). These studies have not been verified.

Several authors propose the use of occupational therapy in the management and treatment of CFS (Cox 1999; Mounstephen and Sharpe 1997). A review of the literature on occupational therapy and CFS concludes, however, that not enough is known about the condition to develop

an adequately tailored approach to treatment (Glozier 2005). Similarly, studies of the efficacy of group work (Friedberg, Leung, and Quick 2005; Soderberg and Evengard 2001; Taylor and Jason 2002) and rehabilitation programmes in the treatment of CFS produce mixed results (Taylor 2005, 2006; Taylor et al. 2006).

Perrin, Edwards and Hartley (1998) claim to show that osteopathic treatment has positive results with CFS patients. The authors were, however, unable to identify what aspect of osteopathic treatment lead to these results and this study has not been repeated.

There seems little consensus with respect to the efficacy of exercise therapy in the management or treatment of CFS. The extent to which deconditioning occurs as a result of CFS is unclear, consequently the need for reconditioning is also unclear. Related management and treatment approaches are similarly inconclusive and have not been independently verified.

2.3.3 Other Management and Treatment Approaches

Various authors have investigated the use of pharmacological doses of nutritional supplements such as vitamin C (Kodama and Kodama 2006), eicosapentaenoic acid and other long-chain polyunsaturated fatty acids (Puri 2007, 2004), magnesium (Cox, Campbell, and Dowson 1991; Takahashi et al. 1992) and polynutrient supplementation (Brouwers et al. 2002). In an independent review of such treatment, Jenkins and Rayman comment that “in general, abnormal biomarkers, at least in CFS, do not appear to reflect nutritional intakes and are therefore a poor basis for suggesting nutritional supplements ... our findings do not support the routine use of pharmacological doses of nutritional supplements in patients with CFS” (Jenkins and Rayman 2005, p.187).

Zachrisson, Regland et al. (2002) claim that repeated doses of staphylococcus toxoid are safe and produce positive immune responses in CFS patients. Goodnick (1999) found that nefazodone relieved some CFS symptoms in three patients. Neither study has been repeated and the limited number of such studies makes it difficult to draw conclusions.

The use of anti-depressants such as bupropion, nortriptyline and venlafaxine in the management and treatment of CFS has been suggested (Thomas and Smith 2006). Limited attention has been given to the efficacy of this approach with no substantive reports of treatment success.

Surawy, Roberts and Silver (2004) report on three studies that use mindfulness-based stress reduction and mindfulness-based cognitive therapy in the treatment of CFS.

These exploratory investigations suggest that mindfulness training, when carried out within the framework of a clear cognitive rationale, is acceptable to patients with CFS ... and can improve mood, quality of life and physical functioning. The first study indicated a significantly greater reduction in anxiety and a reduction in subjective fatigue that

approached significance compared to waiting list controls. These effects were also demonstrated in the second study in which patients acted as their own controls. In addition, the negative impact of fatigue on quality of life was significantly reduced as evidenced by the results in the second and third groups. The consistency of these findings suggests a genuine effect of the intervention. Finally, the introduction of measures 3 months following the end of the third group shows that these improvements, and the significant and positive effects on depression and physical functioning specific to this group, can be maintained in the longer term. It is our view that the promising findings demonstrated in this paper justify a more in-depth study of mindfulness intervention in patients with CFS. (Surawy, Roberts, and Silver 2004, p.108)

The authors suggest that mindfulness provides a useful precursor to cognitive behavioural therapy but may stand alone as an approach to the treatment of CFS. Although these results are preliminary, they are positive and do suggest the need for further investigation. It will be important to see whether subsequent research will support or contest these findings.

Shin and Lee (2005) provide an initial report on the use of Qi therapy (QT) in two case studies of CFS.

The participants in these case studies showed, through their written responses, the impact of QT on their feelings of inner peace and their hopes for a cure. They experienced relaxation of mind and emotions. They also felt the energetic power of Qi and gained strength to overcome their pain and fatigue. Qi therapy also made them strong enough to fight disease with their own energies by enhancing their own Qi. (Shin and Lee 2005, p.141)

Although these preliminary results appear promising, they are very limited. Shin and Lee comment that “more objective clinical measures are required to confirm the general efficacy of QT” (Shin and Lee 2005, p.141).

An isolated study by Masuda, Takashi et al. (2005) reports on the successful treatment of two CFS patients with thermal therapy. This study has not been repeated.

Noteworthy for their more consistent reports of treatment success are four multidisciplinary treatment programmes (Gibson and Gibson 1999; Van Houdenhove, Bruyninckx, and Luyten 2006) (Marlin et al. 1998; Denborough et al. 2003). Although these programmes employ very different treatment methods and modalities including homeopathy and psychotherapy (Gibson and Gibson 1999), cognitive behavioural therapy and graded exercise therapy (Van Houdenhove, Bruyninckx, and Luyten 2006) and a combination of optimal medical management, pharmacological treatment of affective or anxiety disorder, cognitive behavioural therapy, sleep management, activity management, regulation of stimulant intake, reduction of symptomatic medication, cognitive intervention with respect to illness beliefs, family therapy and vocational integration (Marlin et al. 1998), all of these multidisciplinary studies attend to at least one aspect of the psyche and one aspect of the soma. Denborough, Kinsella et al. (2003) are the only authors who attempt to assess what was successful about their multidisciplinary approach to CFS. They conclude that, although it is not clear what creates the success of their

programme, it appears to be the combination of the treatments employed. Why a combinatory approach produces some success is not assessed.

Despite the preponderance of studies on the use of CBT and GET in the management and treatment of CFS there is no clear evidence for the efficacy of these approaches. Numerous other approaches have produced contradictory reports and the majority of this research remains unverified.

This lack of verification and the contradictory nature of reporting often stem from the use of a variety of different diagnostic criteria. There is also a tendency for management and treatment approaches to focus on a selected and often exclusive aspect of the condition. In some cases these studies do not describe the diagnostic criteria employed or their rationale for approaching the treatment of CFS from the perspective taken. This makes comparisons between these studies irreconcilable. Further, there are few comparative studies of management and treatment approaches.

I suggest these inconsistencies with respect to investigating and formulating management and treatment approaches, like the confusions and controversies considered in the previous section, call for a clearer understanding of what this experience is. Clarity with respect to the nature of the disorder could contribute towards a sounder basis on which to develop and assess management and treatment strategies.

Clarifying what the experience of CFS is will require a hermeneutic process by which our understanding of the experience will be informed by developments in the disciplines considered so far. It would be prudent, therefore, to enlist a phenomenological approach to the study of the experience that is open to such a hermeneutic process. Given the breadth of the experience and the confusions and controversies resulting, this hermeneutic process will necessarily be an interdisciplinary one. The extent to which this interdisciplinarity will be required will continue to unfold in the remaining sections of this review.

2.4 Medical and Psychiatric Literature

2.4.1 Psychiatry and Psychology

Both medical and psychiatric literature point towards high levels of co-morbidity between CFS and psychiatric and neuropsychiatric disorders (Lawrie and Pelosi 1995; Rusconi et al. 1994; Hawton and Cowen 1990; Deale and David 1994; Manu, Lane, and Matthews 1993; Shorter 1996), as well as sleeping disorders including narcolepsy (Fossey et al. 2004; MacFarlane et al. 1996; Moldofsky 1995; Schaefer 1995; Ambrogetti and Olson 1994; Manu, Lane, and Matthews 1993; Kempnaers, Bouillon, and Mendlewicz 1994). Psychiatric co-morbidity and high levels

of psychological distress are common in CFS patients to an extent that cannot be considered coincidental (Kane, Gantz, and DiPino 1997; Michiels and Cluydts 2001; Quillian 1995; Wessely 1993). These co-morbidities do not establish CFS as a psychiatric or neuropsychiatric disorder. This research does, however, demonstrate the need to examine such co-morbidity, both in terms of the degree to which CFS may lead to co-morbidity, and in order to clarify what CFS is on its own terms.

The medical and psychiatric literature has described CFS as neuromyasthenia (Strickland et al. 2001; Stricklin, Sewell, and Austad 1990; 1992), neurasthenia² (Abbey and Garfinkel 1991), and asthenia³ (Shahar and Lederer 1990). Each of these explanations indirectly implies a relationship between CFS, hysteria and somatisation processes. Substantive collections, such as *Post-viral Fatigue Syndrome* (Jenkins and Mowbray 1991), and *The Clinical and Scientific Basis of CFS* (Hyde 1992), strongly challenge these views. Whether this challenge has been observed is questionable.

De-Lange, Kalkman, et al. propose that “CFS may be associated with dysfunctional motor planning” and that motor disturbances may be a crucial component of CFS (2004, p.1948). They do not give reasons for this connection. Research shows that the disturbances to cognitive functioning (Short, McCabe, and Tooley 2002; Capuron et al. 2006), motor control dysfunction (de-Lange et al. 2004; Siemionow et al. 2004; Starr et al. 2000) working memory deficits (Caseras et al. 2006; Dobbs, Dobbs, and Kiss 2001), neuropsychological functioning (Quillian 1995; Kane, Gantz, and DiPino 1997; Michiels and Cluydts 2001) and the poor attenuation of attention (Ray, Phillips, and Weir 1993) that have been identified in CFS patients cannot be attributed to depression, anxiety or psychological distress (Michiels and Cluydts 2001; Wessely 1993). These studies potentially inform an understanding of what CFS is not and may provide traction on establishing what CFS is.

The studies considered in this section use a variety of diagnostic criteria. Some do not mention the diagnostic criteria used. They tend not to be concerned with assessing CFS on its own terms but rather in the light of more established conditions.

2.4.2 Immunology

Numerous studies suggest that CFS may be caused by viral infection, most commonly the Epstein-Barr virus (Lundell et al. 2006; Okano, Thiele, and Purtilo 1990; Drago et al. 1996; Mitterer et al. 1995), Rickettsiae and Chlamydiae (Bottero 2000), an enterovirus (Colby 2007),

² Neurasthenia *n.* A disorder characterized by feelings of fatigue and lassitude, with vague physical symptoms such as headache, muscle pain, and subjective sensory disturbances, originally attributed to weakness or exhaustion of the nerves and later considered a form of neurotic disorder. (Oxford English Dictionary 1989)

³ Asthenia *n.* weakness or loss of strength. Asthenic *adj.* describing a personality disorder characterised by low energy, susceptibility to physical and emotional stress, and a diminished capacity for pleasure. (1994)

mononucleosis⁴ (Buchwald et al. 1990), human herpes virus-6 (Wagner et al. 1996; Kato et al. 1992), Coxiella burnetii infection (Iwakami et al. 2005) or various other viral and immunological dysfunctions (Tirelli et al. 1994; Branco et al. 1994; Calabrese, Davis, and Wilke 1994; Fucikova and Petanova 1993; Cannon et al. 1997; Khan et al. 1993; Dechene 1993). Parvovirus B19 infection has similar symptoms to CFS but there is no conclusive evidence that CFS is a case of parvovirus B19 infection (Heneine et al. 1993; Daly, Thorne, and McIntosh 1997; Matano et al. 2003).

Lindh, Samuelson et al. (1996) found no evidence to support the hypothesis that CFS is caused by enteroviruses. Similarly Heneine, Chapman et al. (1993) found no evidence for the hypothesis that a retrovirus of unusual mode causes CFS. In sum, these findings suggest that although viral infection may be a precursor to CFS, continued viral infection is not present in CFS patients.

Immune dysregulation is commonly found in CFS patients (Gupta et al. 1997; Kashipaz et al. 2003; Kennedy et al. 2006; Kennedy, Spence et al. 2004; Levine et al. 1998; Maher, Klimas, and Fletcher 2005; Marotta, Improt, and Pinto 1994; Sacerdote et al. 1999; Shin et al. 2004; Skowera et al. 2004; Pinto 1995; Plioplys 1997; Dechene 1993; Delahunt et al. 1992; Fletcher, Maher, and Klimas 2002; Gaab et al. 2005; Hickie, Lloyd, and Wakefield 1992; Siegel et al. 2006; Tomoda et al. 2005).

Multiple chemical sensitivities and allergies appear to be common forms of this immune dysregulation (Miller et al. 2000; Lindh and Evengard 1999; Vecchiet et al. 2001; Bell, Baldwin, and Schwartz 1998; Lohmann, Prohl, and Schwarz 1996).

Although there does not appear to be a consistent pattern to the immune dysfunction in CFS, immune dysregulation in CFS appears to be centrally mediated (Natelson et al. 1998; Lyall, Peakman, and Wessely 2003). This research needs to be extended.

Since the immune dysfunction present in CFS may not be purely immunological, further investigation would need to occur from an interdisciplinary perspective. Such research may clarify somatic aspects of the condition not presently well understood and could potentially clarify diagnostic criteria and treatment approaches.

2.4.3 Hormonal studies

Various authors have investigated the role of hormones in CFS and concluded that, other than those hormones involved in the hypothalamo-pituitary-adrenal (HPA) axis, there are no significant hormonal abnormalities (Bennett et al. 1997; Garcia-Borreguero et al. 1998; Garrison

⁴Mononucleosis: The condition in which the blood contains an abnormally high number of mononuclear leucocytes (monocytes) (1994).

and Breeding 2003; Grans et al. 2007; Murphy et al. 2004; Sackett-Lundeen et al. 1999; Young et al. 2000). By contrast the HPA axis is found to be dysregulated in CFS patients (Angel et al. 1998; Di-Giorgio et al. 2005; Jerjes et al. 2005; Jerjes, Peters et al. 2006; Jerjes, Taylor et al. 2006; McKenzie et al. 1998; Segal, Hindmarsh, and Viner 2005; Sharpe et al. 1998; Strickland et al. 1998).

CFS patients appear to hyposecrete the stress hormone cortisol. Segal, Hindmarch and Viner (2005) suggest that HPA axis dysregulation in CFS may be due to a reduction in central nervous system (CNS) stimulation of the adrenal glands.

A number of authors have investigated the roles of serotonin and 5-hydroxytryptamine (5-HTP) in the CNS in the dysregulation of the HPA axis in CFS patients. The 5-HTP modulator system in the CNS is clearly consistently disturbed in CFS patients (Berwaerts, Moorkens, and Abs 1998; Cleare et al. 2005; Dinan et al. 1997; Georgiades et al. 2003; Yamamoto et al. 2004). This potentially involves a genetic component which also manifests in immune system dysregulation (Kaushik et al. 2005; Rajeevan et al. 2007).

The pituitary-adrenocortical dysfunction found in short-term shift workers has been compared to CFS (Chattington et al. 1996).

2.4.4 Neurology

A variety of neurological studies have proved inconclusive (Arnold et al. 2002; Lange et al. 1998; Puri 2001, 2006; Badawy et al. 2005; Billiot, Budzynski, and Andrasik 1997; Chaudhuri et al. 2003; Chaudhuri et al. 1997; Greco, Tannock, and Brostoff 1997; Hannestad, Theodorsson, and Evengard 2007). There are, however, a number of areas in which findings have been made.

Neurally-mediated hypotension has been found in CFS patients, particularly in the form of orthostatic intolerance (Barron et al. 1999; Benoit, Wein, and Phaneuf 1999; Calkins 1998; Freeman and Komaroff 1997; Yamamoto, LaManca, and Natelson 2003; Rowe and Calkins 1998; De Becker et al. 1998; Bou et al. 1995). Two studies have shown considerable improvement in the symptoms of CFS by treating neurally mediated hypotension (Thomas and Bell 2000; Bou et al. 1995). These studies have not been repeated.

Numerous neurological studies have observed hypoperfusion and/or low metabolic rate in various regions of the brain in CFS patients (Abu-Judeh et al. 1998; Bested, Saunders, and Logan 2001; Costa, Tannock, and Brostoff 1995; de-Lange et al. 2005; Khan et al. 2003; Natelson et al. 2005; Palaniappan and Sirimanna 2002; Siessmeier et al. 2003; Tirelli et al. 1998; Yoshiuchi, Farkas, and Natelson 2006).

Sherlin, Budzynsky et al. (2007) have investigated characteristic patterns of neural activity in the brains of CFS patients and their healthy identical twins. The authors find significant

differences in brain activity in the limbic system and the left and right forebrain; “the study corroborates that slowing of the deeper structures of the limbic system is associated with affect. It also supports the neurobiological model that the right forebrain is associated with sympathetic activity and the left forebrain with the effective management of energy” (Sherlin et al. 2007, p.1438).

2.4.5 Comparative Studies

Comparisons between Gulf War Syndrome and CFS are common. Kang, Natelson et al. (2003) have examined the prevalence of CFS in Gulf War Syndrome sufferers. Pollet et al. (1998) report that in a comparison of Gulf War veterans who suffered from Gulf War Syndrome those who concurrently suffered from CFS were less likely to report a sudden onset to their CFS. Chester and Levine (1997) have studied the concurrence of CFS and Sick Building Syndrome. Johnson and Natelson (1993) have shown that information processing deficiencies in Multiple Sclerosis and CFS are similar. Although interesting to some parties, these comparisons do not provide insight into ‘what the experience of CFS is’.

Heijmans and de Ridder (1998) have compared CFS and Addison’s disease as examples of chronic illness. Five dimensions that may differ according to the specific chronic illness are identified: identity, time-line, control/cure, cause and consequences. Conclusions to be drawn from this study are unclear. Whether this research lends any credence to the CFS diagnosis or in any way supports the claim that illness is occurring is debatable.

2.4.6 Other Medical Studies

Herrel, Ashton, et al. (2001) suggest that CFS is moderately heritable but do not identify why this is the case.

Van Rensburg, Potocnik, et al (2001) demonstrate identifiable patterns of trace element concentrations in the blood of CFS patients but do not suggest that this is causative.

Several authors have found evidence of significant oxidative stress in CFS patients (Kennedy et al. 2005; Maes, Mihaylova, and De-Ruyter 2006; Richards, Wang, and Jelinek 2007).

Lindal, Thorlacius, Bergmann, and Stefansson (1996) use grid areas to assess the localisation of pain in CFS sufferers and report that the most common sites for pain were the neck, right buttock, chest, calves and lower back. The significance of these localisations and the source of this pain are not identified.

A study using repeated action research cycles focuses on “contextually sensitive forms of language and models for service delivery suitable for people with CFS in a general practice

setting” (Denz-Penhey and Murdoch 1993). The study is largely inconclusive and has not been repeated.

Medical literature that is specific to women principally measures women’s disability due to CFS by considering reduced functional capacity, for example, reduced cardiovascular fitness and stamina (Riley et al. 1990; Sisto, LaManca, Cordero, Bergen, Ellis et al. 1996; Cordero et al. 1996; Sisto et al. 1995), and women’s information processing efficiency (Barrows 1995; DeLuca, Johnson, and Natelson 1993). Articles that examine women’s experiences in these respects briefly attempt to quantitatively assess self-reported degrees of fatigue and reduced functional capacity (Riley et al. 1990; Barrows 1995). Results vary considerably.

Harlow, Signorello, et al (1998) suggest that women with CFS report more gynaecological complications but a lower level of premenstrual symptomatology than controls. Why this would be the case is not discussed.

Medical and psychiatric research on CFS is informative in a number of ways. This research does suggest that CFS cannot simply be considered a psychiatric or psychological disorder. It does begin to establish the degree to which co-morbidity between CFS and psychiatric and psychological disorders occurs. The medical literature shows some promise in establishing specific somatic aspects of the disorder, particularly that certain brain regions are in some way implicated in the condition. These findings are not accurately reflected in the diagnostic criteria for CFS, have not clarified the etiology of CFS and have not been integrated into management and treatment programs. More research needs to be done to clarify and establish these findings and their implications.

Contributions from medicine and psychiatry are often difficult to compare since they are based on a variety of diagnostic criteria and often tend to address an isolated aspect of the syndrome. These studies are not consistently or comprehensively informed by the phenomenology of CFS.

2.5 Psychosomatic Medicine, Psychology and Psychotherapy

2.5.1 General Literature

The literature on CFS that is *not* specific to women from the disciplines of psychosomatic medicine, psychology and psychotherapy provides varying accounts of illness phases (Jason, Fennell et al. 2000) and sufferers coping strategies (Findley et al. 1998; Ax, Gregg, and Jones 1998; Nater et al. 2006; Ray, Jefferies, and Weir 1995; Ray, Jefferies, and Weir 1997). These studies do not demonstrate any consistent patterns.

Research from these disciplines points towards high levels of co-morbidity between CFS and personality disorders (Blakely et al. 1991; Henderson and Tannock 2004; Buckley et al. 1999; Walford, Nelson, and McCluskey 1993; Wood and Wessely 1999), sleep disorders (Stone et al. 1994) mood disorders (Kelly et al. 1999; Stone et al. 1994; Edwards et al. 2001), and an association between CFS and alexithymia (Friedberg and Quick 2007), depression and atypical depression (Buckley et al. 1999; Kirk, Hickie, and Martin 1999; Henderson and Tannock 2005; Moss-Morris and Petrie 2001; Van Hoof, Cluydts, and De Meirleir 2003). Some CFS patients concurrently suffer from seasonal affective disorder or have a disorder which has features of both conditions (Lam 1991). Brunello (1999) suggests that a subgroup of CFS sufferers may represent a variant of dysthymia.

The co-morbidities established by this research do not determine CFS to be a psychosomatic or psychological disorder. Like the co-morbidities established in the medical and psychiatric literature, this research does demonstrate the need to examine such co-morbidity, both in terms of the degree to which CFS may lead to co-morbidity, and in order to clarify what CFS is.

Shorter (1993, 1997) places CFS within the history of somatisation⁵ disorders in the North American context. Butler (2001) and Howlett and Lindegger (1996) claim to identify the somatisation tendencies of CFS sufferers and suggest that somatisation may be a consequence of attributional style. CFS is attributed by Garralda (1992) to the somatisation of distress in childhood. These studies do not provide clear explanations for what somatisation represents as a process. They do not comment on how or why somatisation may be occurring in the case of CFS. In this literature, somatisation as an explanatory device does not shed light on how CFS might be effectively managed or treated. Or, in broader terms, as it is used here, somatisation does not lead to an understanding of how this form of suffering might be attended.

2.5.2 Literature specific to Girls and Women

A number of studies suggest that CFS is a modern form of neurasthenia⁶ (Wessely 1997; Abbey and Garfinkel 1991; Saltzstein et al. 1992). Despite increasing challenges (Luthra and Wessely 2004) to this perception these studies continue to carry considerable influence in the research community. They are widely cited and referenced.

⁵Somatisation disorder is characterised by:

Recurrent, multiple somatic complaints for which medical attention is sought but which have no apparent physical cause are the basis for this disorder. Common complaints include headaches; fatigue; allergies; abdominal, back, and chest pains; genitourinary symptoms; gastrointestinal symptoms; symptoms suggesting a neurological disorder; and heart palpitations (Davison and Neale 1994, p.169).

⁶“Neurasthenia *n.* a set of psychological and physical symptoms, including fatigue, irritability, headache, dizziness, anxiety, and intolerance of noise. It can be caused by organic damage, such as head injury, or it can be caused by neurosis (1994)”.

Psychosocial factors in adolescent girls are seen as a contributing factor to CFS in adolescents and CFS is presented as closely related to anorexia nervosa and bulimia nervosa (Pelcovitz et al. 1995). It is not uncommon for women with either anorexia nervosa or bulimia nervosa to be initially misdiagnosed with CFS (Griffiths et al. 1996). These relationships are not explored in depth and these studies do not help to clarify what CFS is.

Tuck and Wallace (2000) use the Derogatis Stress Profile (DSP), Spielberger Trait-Anger Scale, Ways of Coping Survey, Perceived Stress Scale and Profile of Moods States (POMS) Survey to confirm that CFS disrupts women's quality of life, relations with others, self perception and career. Goodwin (1997) has explored the links between marital relationships and health in women with CFS, reporting on the views of both husbands and wives. Both of these studies identify substantial ways in which CFS disrupts sufferers' lives. Fischler, Cluydts, et al. (1997) argue that high levels of anxiety in women CFS sufferers may be linked to a longer duration of illness. These ideas are echoed in Walters and Charles' (1997) claim that the unpredictability that an illness state produces in women's lives increases anxiety for CFS sufferers. Wheeler (1992) focuses on the specific issue of self-blame in Californian women CFS sufferers. This is the only published study identified in this review that uses a phenomenological approach. The study is not concerned to describe the experience of CFS as a whole. These findings are important and arguably need to be reflected in management or treatment programs for CFS sufferers. In isolation, however, this research does not provide a comprehensive approach to CFS.

Bell, Baldwin, et al. (1998) claim that early life stress and negative paternal relationships can be linked to chemical intolerance and CFS in middle-aged women. Why this would be the case is not explored.

To assess the coping strategies of women with CFS Saltzstein, Wyshak et al. (1998) employ the Beck Depression Inventory, Sickness Impact Profile, Defence Mechanism Rating Scale, a modified Karnofsky scale, and semi-structured interviews. The authors report:

Findings suggest that improved health is associated with a physician who made a relatively early diagnosis and was perceived by her patients as optimistic about prognosis. ... Improvement was also associated with subjects feeling that their physician believed that they were ill, offered them multiple treatment options, and allowed for frequent, lengthy medical visits in which they actively participated in their health care. (Saltzstein et al. 1998, p.312)

This study highlights the need for patient validation that legitimises illness experience. Such validation appears crucial to the success of the patient-practitioner relationship and recovery from illness.

Åsbring and Närvänen (2004) examine the strategies that women with CFS employ to gain power and control during health care processes to enable them to manage their illness and influence health care providers. The authors report that in interactions with care-givers women with CFS use exiting, demonstrative distancing, non-compliance, confrontation, making demands and persuasion/insistence techniques to gain the opportunity to have mutual influence over the actions taken in their treatment process. Women perceive gaining knowledge about their illness as a means to exert control over their illness experience.

A personal account of the difficulties involved in convincing others that CFS is a real disease is offered by Phyllis Chesler (1998) who is a psychologist by profession.

Moss-Morris, Petrie et al. (1996) examine the relationship between functioning and illness perceptions. They conclude that illness perceptions have more influence on levels of disability than the coping strategies that participants have learned. The authors observe that participants with a strong illness identity who believed their illness was out of their control, stress induced, and likely to have serious consequences, were the most disabled. In contrast, in qualitatively analysed interviews with twenty CFS sufferers, Ax, Gregg, and Jones (1998) claim that women with CFS who believed in a purely organic etiology felt they had little personal control over their illness, whereas those who saw stress as a cause of their CFS made efforts to change their lifestyles. Ax, Gregg and Jones (1998) suggest that for CFS, illness representation within treatment should focus on manageability, seriousness, personal responsibility and the understandings of external causes. This is linked to the disease-specific nature of illness representation (Ax, Gregg, and Jones 1998). Findley, Kerns, Weinberg, and Rosenberg (1998) claim that perceptions of self-efficacy are linked to the experience of CFS symptomatology. Similarly Heijmans and de Ridder (1998) state that illness cognitions and representations are closely linked to coping behaviour and adaptive outcomes. They assert that subjects who cope with their illness in a 'passive way' report more mental health problems, less vitality and more physical and social impairment. These studies on illness perception use widely differing approaches and do not establish any consistent conclusions.

These findings are important and arguably need to be reflected in management or treatment programs for CFS sufferers. This research does not, however, provide a comprehensive approach to CFS and provides limited contributions to a fuller understanding of what the experience of CFS involves.

Holland (1997) and Simpson (1997) focus on the relationship between mother and child in women with CFS and suggest that analytical psychotherapy may be an appropriate approach to

treatment. Driver (2005) also enlists a psychotherapeutic approach and focuses on the internal regulation of the relationship between psyche and soma.

In the experience of the work with Jane it would seem that her early maternal relationship did not enable her to develop the internal capacity to reflect in relation to self and body and that this resulted in an unconscious failure to separate and differentiate between psyche and soma. The importance of the analytic process is that it enabled Jane, through the disintegrative-integrative processes inherent in it, to develop the capacity of her ego to relate to her body-self and her psyche-self so that the needs, issues and conflicts could be struggled with, made more conscious and not collapse into symmetry and confusion. ... Analytic work generates a reflective and mindful place in which there can be an inter-relational dialogue in which both body and psyche can be considered as inter-linked as well as differentiated. ... Whether we are dealing with physiological causes and, ultimately a physiological cure, or the psychological impact of psychological experience, the psyche and soma interact in a manner we can never fully understand. (Driver 2005, p.170)

Driver's focus on the relationship between psyche and soma is almost unique to all the literature reviewed. The reason for her assertion that the relationship between psyche and soma cannot be understood is not specified. These psychotherapeutic studies involve a small number of cases and have not been repeated.

Research conducted from the perspectives of psychosomatic medicine, psychology and psychotherapy unanimously assumes that CFS is principally an issue of the psyche. There are no clear reasons given for this assumption. These studies tend to focus on an isolated aspect of the CFS experience. None of this literature is informed by or develops a thorough understanding of the overall CFS experience, particularly for women. Although some of these studies present findings that could contribute towards management and treatment programs, as a whole, this literature does not provide a clear picture of the disorder. Like the literature considered in earlier sections of this review, these studies use a variety of different diagnostic criteria and some do not specify the criteria used. The picture of what CFS is remains inconsistent.

2.6 Sociological Literature

2.6.1 General Literature

The sociological literature on CFS that is *not* specific to women considers the stigma surrounding the CFS diagnosis (Green, Romei, and Natelson 1999; Looper and Kirmayer 2004), sufferers well-being and quality of life (Schweitzer et al. 1995; Van-Damme et al. 2006; Hardt et al. 2001), the levels of disability experienced by sufferers (Morantz and Torrey 2003; Bombardier and Buchwald 1996), sufferers' difficulties in securing disability benefits (Hammond 2002; Barbara 1998; Assefi et al. 2003), general practitioners' perceptions of CFS (Raine et al. 2004), secondary school teachers' perceptions of CFS (Everett and Fulton 2002), sufferers' beliefs about their illness (Clements et al. 1997), critical life events immediately prior

to illness (Mayer 2000; Hatcher and House 2003; Blomkvist, Lindh, and Evengard 1999), childhood experiences of illness and parenting in adult sufferers (Fisher and Chalder 2003), caregivers' experiences (Ferrari and Jason 1997), sufferers' illness narratives (Bülow and Hydén 2003; Hughes ; Guise, Widdicombe, and McKinlay 2007; Horton-Salway 2001), narrative constructions of the self (Weinberg, Louw, and Schomer 1994) and identity (Horton-Salway 2001; Whitehead 2006; Whitehead 2006).

Although some of these studies present findings that could contribute towards management and treatment, they are not informed by and do not develop a comprehensive understanding of the experience of CFS. Inconsistencies with respect to diagnostic criteria are also prevalent

2.6.2 Sociological literature Specific to Women with CFS

Given the significant levels of disability that CFS produces in women's lives, and the preponderance of women sufferers, the paucity of sociological literature on CFS and women is striking.

In a cross-sectional study of 40 adolescents Van de Putte, Doornen et al. (2006) claim to show that the mothers of adolescents with CFS exhibit similar psychological symptoms. They conclude that "the clustering of symptoms in mother and child suggests genetic transfer and gene-environment interaction" (van-de-Putte et al. 2006, p.2078). This study has not been repeated and these conclusions are not directly supported by any other research.

Jha, Massen and Lindow (1999) suggest that fatigue in women with CFS may improve during the third trimester of pregnancy and puerperium. These conclusions are based on what is probably the only study of severe CFS and pregnancy and involves the experience of one participant. Schacterle and Komaroff have compared pregnancies in women with milder CFS before and after illness onset and conclude "pregnancy did not consistently worsen the symptoms of CFS. Most maternal and infant outcomes were not systematically worse in pregnancies occurring after the onset of CFS" (2004, p.401). This study has not been repeated.

Åsbring and Närvänen (2002) have investigated the experiences of stigmatisation and discrimination reported by women with CFS. According to participants most of this stigmatisation occurs due to the controversy surrounding the CFS diagnosis in response to the breadth of symptoms they present. Åsbring and Närvänen (2002) describe how women negotiate these experiences of stigma. This study highlights the importance of clarifying the diagnostic criteria for CFS. This may reduce the controversy surrounding the diagnosis and make the syndrome, and its experience, more communicable.

Reynolds and Vivat (2006) have assessed the use of art therapy for women with CFS. They suggest that although art therapy is not a curative therapy it may allow "those who live with

serious illness to unfold the cramped self, uncover losses and strengths, and gain the courage to begin a process of reclamation of story and life” (Ferris and Stein 2002, p.47 in Reynolds and Vivat 2006, p.444).

An isolated qualitative case study has been conducted on the experiences of two women who received treatment with the immunomodulatory drug Ampligen. Treatment is reported to have created a remission of CFS symptoms. This study has not been repeated.

Teven (2004) examines the contextually embedded narratives of self and enigmatic illness presented by women with fibromyalgia and CFS. Teven is focused on fibromyalgia, however, her doctoral thesis provides some insight into CFS.

Using grounded theory, McCue (2004) has examined the experiences of women who have recovered from CFS with respect to their experiences of receiving a diagnosis. McCue writes:

In conclusion, the findings of this study show that those with CFS experience problems with diagnosis in terms of organic versus a mental health approach, and with acceptance and belief that they are actually ill, which appear to be challenges that are unique to CFS although this also applies to some extent to illnesses that are categorised as functional somatic syndromes. (McCue 2004, p.200)

This is the only study identified that considers the experiences of women who have recovered from CFS. The focus of the research is purely concerned with women’s experiences of diagnosis.

Richman, Jason et al. (2000) analyse the gender biases that underlie the social construction of chronic illness states, exploring CFS as an example of these processes. They claim that the tendency within the literature to focus on CFS as a female illness caused by psychiatric and psychosocial factors detracts from efforts to examine the disorder at a biomedical level. The authors argue that the failure to find a viral etiology for CFS has led to an illness construction in the biomedical literature that is similar to that which initially surrounded multiple sclerosis: a disease initially considered to be a form of neurosis specific to women. Despite this caution against characterising CFS as simply “all in the mind”, this tendency continues to pervade research. Caplan (2001), herself a researcher in the area of psychology, has given a phenomenological account of her own experiences of CFS and multiple chemical sensitivities. Caplan comments:

Until now, I have not written about the misinterpretation of real physical problems, especially in women, as psychological ... and psychopathological. Without my knowing it, for many years the latter was exactly what was happening to me. Perhaps most disturbingly, I, too, misinterpreted physiologically-based problems as psychological because of my lack of knowledge first about the very existence and later about the nature of what is now variously called Chronic Fatigue Syndrome, Chronic Fatigue Immune Dysfunction Syndrome, Multiple Chemical Sensitivity, Fibromyalgia, and various other things outside North America. (Caplan 2001)

Caplan (2001) identifies a genuine problem, one that clearly impacts upon the diagnostic process for women with CFS.

Clarke (1999) has compared the experiences of men and women in seeking a diagnosis.

The evidence in this paper then points to a clear dichotomy between the similar ways that men and women experience the disease and the differences in the ways that they are treated by the medical profession. This analysis adds weight to the hypothesis that explains gender differences in illness as the result of medical views of the psycho-pathological nature of women and their bodies, and their proclivity to seeing women's problems as psychogenic. (Clarke 1999, p.132).

Richman and Jason (1998) make a similar observation in their study of the differences between the opinions of sufferers and the medical community.

Within the context of a social construction of illness perspective, we have suggested that the medical community has devoted major attention to the presumption that CFS is largely rooted in psychiatric and/or social stress factors, while the CFS patient population has maintained that CFS is primarily an illness with a yet to be identified biomedical etiology. (Richman and Jason 1998, p.24)

These studies concerning diagnosis demonstrate the importance of clarity with respect to the diagnostic criteria. Whether gender bias is occurring with respect to any aspect of the syndrome is difficult to assess, however, without a comprehensive assessment of what the experience of CFS involves.

What Richman and Jason (1998), Clarke (1999), Caplin (2001), Richman, Jason et al. (2000) and McCue (2004) tend to overlook, however, is the assumption that the condition can or should be ascribed to either a somatic or psychogenic etiology. They are not alone in this assumption which can be found throughout the more general sociological literature on CFS (Banks and Prior 2001; Cooper 1997; Stein 2001; Ware 1992).

The sociological studies of CFS presently available do not substantially clarify what social factors may contribute to or exacerbate the occurrence of CFS. They do not provide a comprehensive assessment of how the disorder is received socially or how this may impact on CFS sufferers' experience of illness. Similar to the literature considered in earlier sections of this review, the sociological studies considered use a variety of diagnostic criteria, tend to focus on an isolated aspect of the CFS experience and are ill-informed of the overall CFS experience, particularly for women. Some of these studies may contribute towards management and treatment programs, particularly how such programs might best be presented and offered.

2.7 The New Zealand Context

Little research has been undertaken on CFS in New Zealand. The studies of Vallings (1989, 1993), Murdoch (1987, 1989, 1989, 1992), Blakely, Howard et al. (1991) and Levine, Snow et

al. (1997) are the main published investigations available on CFS in the New Zealand population. The diagnostic criteria these authors enlist are not consistent and their research has not been repeated.

Murdoch's work is the principle source from a medical perspective. In 1984 Murdoch established that of 109 members of the Otago/Southland M.E./CFS Support Group of New Zealand "72 percent had severe to moderate problems at work (many lost their jobs), 40 percent had severe to moderate domestic problems and 28 percent had financial problems" as a result of their illness (Murdoch 1987, p.53). Based on a random sample of New Zealand general practices, Murdoch concluded that approximately 74% of CFS sufferers in New Zealand are women between 20 and 50 years of age (Murdoch 1987, p.53). A study of the greater Dunedin area showed "the prevalence [of CFS to be] at least... 127 per 100,000. Thus this syndrome has about the same prevalence as Parkinson's disease and is more prevalent than multiple sclerosis" (Murdoch 1987, p.53).

In New Zealand, CFS has occurred in geographically specific epidemics (Levine et al. 1997) but most often occurs on a sporadic basis throughout the community. In a ten year follow up study of the 1984 outbreak of CFS in the West Otago area, Levine, Snow et al. (1997) report female sex to be a risk factor for CFS and suggest that early recognition and diagnosis of CFS by physicians contributes towards a higher rate of recovery. The authors do not examine the reasons why early diagnosis is useful or why female sex is a risk factor.

Vallings (1989, 1993) has evaluated the efficacy of group therapy, hormonal treatment and the use of alternative medicine, claiming that group therapy, complete rest and gradual exercise build-up were most successful. Her five year study of 200 patients (Vallings 1989) and 10 year study of 500 patients (Vallings 1993) identified depression (often due to the considerable reduction in expectations regarding possible achievement in work, study, sporting commitments, etc.) and symptoms suggestive of anorexia nervosa as important contributing factors to CFS, particularly in women. This study has not been repeated and these findings do not support the hypothesis that CFS is a form of depression or anorexia nervosa but they do suggest that these factors may need to be addressed by management and treatment programs.

Blakely, Howard et al. (1991) have compared CFS to chronic pain and suggested that CFS could be considered a subclass of chronic pain. This isolated study has not been repeated.

Scott's (1993) Masters thesis on the use of selenium in treating CFS; an unauthored working paper entitled *ME : Sickness, Stigma and Self* (V.U.W. Sociology Dept date unknown), Horne's (1990) Masters thesis, *The Social and Psychological Effects of ME in New Zealand and the Problems of Recognition*, which offers a Maori perspective; and Anne M. Ny's (1987)

unpublished paper, *A Study of the Medical, Social, and Economic Implications of the "Illness" for 100 Sufferers in Canterbury, New Zealand*, all point towards the need for a systematic phenomenological analysis of New Zealand women's experiences of CFS. They do not give reasons for this suggestion. Like the published research above, these studies do not use consistent diagnostic criteria and have not been repeated.

Within New Zealand, CFS has attracted considerable controversial media coverage. Information is available from ME support groups (M.E. Action Campaign 1993) throughout the country and there are a number of self-help books by New Zealand authors, such as Steincamp's (1988) *Overload* and Jeffreys' (1982) *The Mile High Staircase*. Vayda's (1991) *Chronic Fatigue* offers self-help advice from an Australian perspective. Such publications have become popular worldwide by offering advice to sufferers and, in some cases, recounting the author's own experiences of CFS. The medical community in particular have found these accounts inadequate for a variety of reasons⁷. The self-help literature does not represent a systematic review of sufferers' experiences of the disorder. Media coverage has been sporadic and selective.

The inconsistencies within the New Zealand research reflect those consistent within the broader research community. Although Murdoch's work provides an approximate estimate of the female prevalence of CFS, this has not been substantiated and the reasons for this preponderance have not been examined. Diagnostic criteria used in these studies vary which makes comparison difficult. Existing research has not been verified and the diagnosis continues to attract controversy within the media, general practice and the research community generally.

2.8 Conclusion

The literature considered here provides a broad view of the research on CFS. This is necessary background for a comprehensive exploration of the condition. The review reveals three common themes within the research: the lack of clear diagnostic criteria, a propensity to analyse CFS from the perspective of disciplines, the boundaries of which tend to assume a dichotomy of mind from body, and a lack of a comprehensive phenomenological understanding of CFS.

The lack of uncontroversial and well-established diagnostic criteria systematically undermines the progress of research. Present studies are largely irreconcilable because research has been implemented on the basis of varied and unclear diagnostic criteria. This makes the verification of results untenable. What these studies do offer, consequently, has not begun to

⁷Murdoch refers to one such book as an "intriguing piece of science fiction [which] holds within it more than a grain of truth, but while time discovers that truth, there will continue to be controversy about both syndrome and treatment" (Murdoch 1989, p.213).

accrue into a comprehensive composite picture of CFS. This is compounded by the propensity of studies to consider specific and limited aspects of the syndrome.

The literature reviewed does suggest that CFS cannot simply be considered a psychiatric or psychological disorder, although there is significant co-morbidity between CFS and various psychiatric and psychological disorders.

The biomedical literature shows some promise in establishing specific somatic aspects of the disorder, in particular, that certain brain regions are in some way implicated in the condition. These findings need to be accurately reflected in the diagnostic criteria, further research and integrated into management and treatment programs.

None of these literatures are informed by a comprehensive understanding of the experience of CFS, particularly for women. Where a phenomenological approach has been employed, such as within the sociological literature, the research tends to focus on an isolated aspect of the experience of CFS. This does not provide a comprehensive overview of sufferers' experiences. Such phenomenological studies are limited in their ability to inform further research.

I suggest that a more comprehensive understanding of the phenomenality of CFS could significantly aid future research. Clarity with respect to the nature of the disorder would potentially lead to a clearer understanding of its diagnostic criteria. This would facilitate progress in other areas of research, particularly etiological studies and the development of management and treatment strategies.

Where the medical and psychiatric literature tends to reduce the problem of CFS to the somatic, psychology, psychosomatic medicine and psychotherapy tend to reduce CFS to the psyche. Consequently, these literatures are prone to reinstating a mind/body dichotomy that perpetuates disciplinary biases and boundaries. This makes a more comprehensive or interdisciplinary approach to CFS difficult. The pervasive assumption is that the condition can or should be ascribed to either a somatic or psychogenic etiology and that when this debate is settled it will resolve much of the controversy that surrounds the condition.

That it is possible to reduce this syndrome to either somatogenic or psychogenic origin I believe is an open question. Perhaps, instead, it is the duality of mind and body that is the problem. Given the evidence, I would suggest a comprehensive phenomenological investigation that does not assume this dichotomy stands to more accurately characterise the condition. This could provide a firmer platform for further research.

Conducting phenomenological research that avoids the mind/body dichotomy poses several challenges.

Clarifying what the experience of CFS is will require a hermeneutic process whereby the phenomenological data informs the third-person studies and vice versa. It would be prudent, therefore, for any phenomenological or biomedical study of the condition to be open to such a hermeneutic process. Given the somatic and psychological breadth of the experience this hermeneutic process will necessarily be a broadly interdisciplinary one.

Further, I suggest this review shows that existing research suffers from limited conceptual frameworks for the possibilities of relationship between psyche and soma. This conceptual limitation considerably contributes to the fragmentation of the view of the experience. It tends to focus approaches to the problem on only one side of the mind/body dichotomy. The pervasive assumption within psychosomatic medicine, for instance, that somatisation is necessarily pathological and the tendency within psychology and psychotherapy to psychologise CFS are predominant examples of such limited conceptual frameworks at work. Both result in an absence of understanding with respect to the bodily contributions to the experience. In contrast, studies that show the most promise in attending to the management and treatment of the disorder appear to be conducted from an interdisciplinary and multidimensional perspective and attend to both mind and body. How these studies better succeed is not clear. They provide limited insight into the overall experience but they do point towards the need to adequately tackle contributions from both soma and psyche. This research endeavours to enlist conceptual tools that more adequately attend to the relationship between mind and body.

To begin to address these lacunae the present research aims to provide a comprehensive phenomenological examination of thirty New Zealand women's experiences of CFS, one that is open to a hermeneutic process of exchange with third-person research, and, therefore, allows for interdisciplinary engagement. Such a comprehensive examination will need to attend to the different stages of the illness experience, including recovery, and stands to contribute to a clarification of the diagnostic criteria for CFS and to potentially guide treatment and management approaches, particularly those which are multidimensional or multidisciplinary. The present research aims to attend to the 'psychosomatic' complexity of CFS in a manner that is not reductive. Rather, the research will need to enlist a conceptual framework for the interdependence of psyche and soma that does not limit understanding of this exchange to pathology.

3. The Problematic

3.1 Introduction

To consider the phenomenality of CFS is to consider (a) a form of suffering, (b) an illness process and (c) a psychosomatic phenomena. This chapter introduces each of these problematics.

How and why the research considers suffering from a phenomenological perspective is introduced in section 3.2 and developed in chapters 4,5, and section 7.6.11.

The structure of this research is partially inspired by the Prasangika definition of suffering. That this is the case and how this definition of suffering is used in the research is presented in section 3.5.

This research focuses on illness as a process. The various illness processes that are considered and why this approach is taken is discussed in section 3.4.

In order to step differently to the professional transformations of the condition found lacking in the literature review, this research enlists conceptual tools that address the relationship between mind and body from a non-dual and embodied perspective. Further, the research endeavours to ensure that the role of the body in the generation of meaning, experience and language is given presence. By so doing this study endeavours to approach the psychosomatic more successfully. This theme is introduced in section 3.3 and developed further in Chapters 4,5, and 6.

3.2 Suffering and Its Professional Transformation

Considering suffering is a complex proposition: “we have gone beyond the point where the subject of suffering can be examined as a single theme or a uniform experience (Kleinman, Das, and Lock 1997 p.xxiv)”. There are no singular definitions of suffering, illness or the subject (Pitkin 2001). Cassell comments from the perspective of medicine.

Problems of staggering complexity arise when we attempt to understand all the known dimensions of person and their relationship to illness and suffering. These problems are no greater than those initially posed in trying to find out how the body worked. The difficulty is not how to finish solving the problems – it’s how to start. But if the ends of medicine are once again to be directed toward the relief of human suffering, the need is clear (Cassell 2004 p.45)

How and where to start inevitably involve processes of interpretation. Kleinman brings this issue into focus in terms of the professional transformations to experience that inevitably result from enlisting a specific disciplinary perspective.

At least by implication, psychiatrists are held to trivialize the experience of their subjects, and even perhaps render them more difficult to work through. The anthropological accounts, then, claim to make a fundamental critique of the psychiatric transformation of that

irreducible existential quality of illness. That professional transformation, it is claimed, sometimes with more than a little suggestion of moral superiority, re-creates human suffering as inhuman disease (J. Cassell 1991). The anthropologists' *interpretive dilemma* is that they participate in the same process of professional transformation. The interpretation of some person's or group's suffering as the reproduction of oppressive relationships of production, the symbolization of dynamic conflicts in the interior of the self, or as resistance to authority, is a transformation of everyday experience of the same order as those pathologizing reconstructions within biomedicine. Nor is it morally superior to anthropologize distress, rather than to medicalize it. What is lost in biomedical renditions – the complexity, uncertainty, and ordinariness of some man or woman's world of experience – is also missing when illness is reinterpreted as social role, social strategy, or social symbol ... as anything but human experience (Kleinman 1995 p.96).

Despite the lack of epidemiological studies, current research does suggest that CFS impacts sufferer's experience of well-being in numerous social and psychological ways. These factors do warrant further investigation (Berkman 1981). Equally medical and psychiatric studies suggest that further investigation into the somatics of CFS stand to be necessary and useful. None the less, my literature review suggests that Kleinman's observation is correct. The professional transformations represented in current research on CFS have not produced an interpretation of CFS that adequately attends to the nature of the experience or alleviates this experience of suffering. Controversy continues to surround the diagnostic criteria, stigma and shame accompany the diagnosis, and existing management and treatment strategies offer very limited success. Factors such as these give disorders a social positioning that is itself a potential source of suffering (Kleinman 1988).

This research takes the exploration and interpretation of the experience of CFS as its place to start. The goal of the present research is to examine CFS in a manner that allows the experience to push against the present disciplinary representations and from a perspective that can potentially alleviate suffering.

While experience is shaped by representations, it can also push against these representations – resisting language, bending it in new directions, and distorting the received ways of expressing distress and desperation so that these distortions themselves transform the experience of suffering (Kleinman, Das, and Lock 1997 p.xiv).

A first-person psycho-phenomenological approach (Vermersch 1999; Vermersch 2009) is enlisted to open a space in which subject's experiences of CFS might be voiced differently. The focus of this research, therefore, is principally phenomenological rather than psychological, sociological or biomedical. In order to avoid a professional transformation that reinstates the mind/body dichotomy the interpretation of this phenomenological analysis will be underpinned by an approach to the psychosomatic complexity of CFS that does not assume that any relationship between mind and body is necessarily pathological. Why this is necessary is introduced in the next section. The conceptual tools that will be enlisted to achieve this are

presented in Chapters 4,5, and 6. The definition of suffering utilised in the research is presented in Section 3.5. By addressing the phenomenality of CFS in this way it is hoped that the research will lay the grounds for future research from other perspectives, including the social, psychological and biomedical.

3.3 Establishing an Approach to the Psychosomatic

In the conclusion to my literature review I argued that the research considered therein is operating with inadequate conceptual tools (principally the concept of somatisation) with respect to the relation between mind and body. Kleinman provides a critical assessment of somatisation within the west and cross-culturally (Kleinman 1986). Kleinman and Kleinman define somatisation as “the expression of personal and social distress in an idiom of bodily complaints and medical help seeking” (1985 p.430). They comment:

Psychiatrists and psychologists emphasize the study of somatization as maladaptive coping style or expression of depression and other forms of psychopathology. They view somatization as a means of coping with emotional problems (discharging anger in a sanctioned way, fulfilling dependency needs, sanctioning perceived failure). Most have not considered its normative and adaptive aspects, nor have they detailed its function as discourse strategies to open up behavioural options (e.g., time of work, change of jobs, marital separation), to control interpersonal transactions (except where family therapists have focuses on its pathological role within the family), to gain greater access over scarce resources (e.g. disability payments), to empower the relatively powerless (in gender-related work and political settings). These are precisely the problems that require an interpretive approach, be it ethnographic, historical, or integrated with quantitative analysis (Kleinman and Kleinman 1985 pp.474-5).

What the authors here question is the assumption that somatisation always represents a form of psychopathology. They acknowledge that somatisation may have functions that are constructive for the individual, for instance, that somatisation may provide a means by which the individual can leverage their situation to their advantage. This is an important observation, however, it does not render somatisation any more adequate a concept for the present undertaking. What is required is a conceptual tool that explains the contributions of mind and body to experience, meaning and language.

Disciplines that study the body directly, or reduce the mind to the body, tend to employ mechanistic and atomistic kinds of concepts. These kinds of concepts, Gendlin argues, are incompatible with the more ‘ecological’ first-person concepts used to study experience. Gendlin calls for the use of process-based concepts in order to bridge this gap (Gendlin 2000, 1992). I agree with Gendlin’s call for the use of process-based concepts and would argue that this potentially facilitates acknowledgement of the bodily contribution to experience through the

vehicles of meaning and language is a critical consideration in assessing psychosomatic phenomena.

Borne out in the work of theorists such as Husserl and Heidegger (Gendlin 1992), Derrida and Foucault is the pervasive interpretive assumption that there is no means by which the body can contribute to our understanding of experience (Gendlin 2002). This makes invisible the contribution of the body to an understanding of experience and the language forms and concepts that we derive from experience.

The relativism that is current today in Western culture stems from this one-way direction, from *interpretive* approaches to cultural practice, to people, to bodies. A belief in relativism (and nihilism) is so widely held today because it is assumed that all experience is derivative from forms, that these forms are given by history, and that they are therefore utterly relative. ... There is also new programming, of course, but as relativist thinkers see it, it is always from the top down, from the outside in, never *from experience*. ... Such thinkers think that nothing new can ever come from within the body. (Gendlin 1992 pp.195-6)

In other words, it is often assumed that the body can only be interpreted with the mind and that the body does not offer a reciprocal interpretation and contribution to the mind. This interpretive assumption leads to constructions of somatisation that assume these processes are pathological and unidirectional from mind to body.

To do justice to an experience such as CFS this interpretive assumption must be thoroughly addressed. I argue that it is the dichotomisation of body from mind that is the problem. Consequently simply adopting a bidirectional approach, such as that provided by the introduction of concepts such as somatisation or psychologisation, leaves this dichotomy in tact. To overcome the dichotomy a non-dual embodied approach is necessary to both the exploration of the expression of CFS by sufferers and the conceptual interpretation of this expression. It is crucial that the contributions of the body to the experience be visible, that the ‘voice’ of the body as much as the mind be heard. What is needed is an approach that acknowledges the role of the body in creating meaning, experience and language. In this way the body can inform the exploration and interpretation of the CFS experience. The principal conceptual tools this research enlists towards these ends are Gendlin’s theory of meaning (Gendlin 1962) and enactive cognitive science. Gendlin’s theory of meaning is presented in chapter 6 and the necessary aspects of the enactive approach are presented in chapter 4.

3.4 Engaging with Illness as a Process That Includes Recovery

In considering any study of experience, it is important to consider what kind of knowledge is being generated about that experience. Gendlin argues that knowledge about experience needs to

be process-knowledge. He argues, when seen as such, it becomes possible to appreciate the precision attainable with this kind of knowledge.

This kind of knowledge seems unscientific if we judge it by the precision of the distinctions between units in reductionistic physics, but if you examine it in terms of *kinds of processes*, then its distinctions appear well-precisioned. There are distinctions between processes and sub-processes, and between desired and undesirable variants. Pitfalls are often well-defined. The conditions for obtaining a process, and the definitions of outcomes are often precise. (Gendlin 2000 p.7)

To appreciate the precision with which my subjects express their experience of suffering from and recovering from CFS a process-knowledge model is required. The research subjects describe different moments to their experience, stages and self narratives. Becom-ing ill, be-ing unable to do, suffer-ing and becom-ing well are all processes. These are what Gendlin describes as the string of continuously reflectively created wholes (Gendlin and Johnson 2004). Each of these reflectively created wholes is a process of meaning. Meaning is, itself, a process (Gendlin and Johnson 2004). Investigating what kind of experience CFS is involves asking what processes make up this experience and what the meanings of those processes are. What stands to provide crucial insight into the nature of the illness process and its treatment (potentially the alleviation of this suffering) is the process of recover-ing. In effect, asking what kind of experiential process CFS is entails the additional question: what is the experience of recovering from CFS? In other words, how does the process end, what occurs next, and what do these elucidate about the illness process? Also, the examination of recovery potentially directly contributes to the development of management and treatment programs by discovering what wellness and recovery entail for CFS sufferers.

3.5 A Definition of Suffering and its Alleviation

To understand suffering and its alleviation the research enlists from the Mahayana Buddhist wisdom tradition the Prasangika-Madhyamika philosophical approach to the definition of suffering. Suffering is a topic of ethical, philosophical and practical importance to Prasangika thought.

This approach considers practices of exploration and interpretation crucial to the definition and alleviation of suffering. Pitkin states:

The initial problem is the egocentric self. From this flow the intertwined philosophical and moral errors of absolutism, nihilism, and the desire to escape suffering – to run away and be somewhere else. All of these, unchecked, obstruct compassion and ethics, and lead to further suffering (Pitkin 2001 p.233).

What forms the basis of the egocentric self is adherence to the belief that the reality we know through our senses (one that appears to be constantly changing against a stable background of

self) gives access to a real sense of self that has an intrinsically permanent identity. This apparently unchanging self then becomes a source of self-centricity or ego-centricity. Attachment to this sense of self permanence leads to the desire to exclude that which is different and suffering arises as a consequence. For the ego-self change and impermanence become the source of an absolute experience of loss and this is the root of the sense of suffering. This leads to a desire to escape from experiences of change.

From the Prasangika perspective, the ‘cure’ for suffering requires relinquishing the belief in the permanence of the self and, by extension, all other phenomena.

For Prasangikas, liberation from the egocentric self, from all absolutisms, and from the desire to escape, lies in the wisdom of non-dual understanding, in which the pivotal scandal is the emptiness of all phenomena (Pitkin 2001 p.233).

For the self this emptiness becomes a source of liberation from suffering and lends the freedom to be open to change. The self is free to be ‘virtual and ontologically fragile’ (Scharmer 2000). The non-duality of self and other becomes a source for an intersubjective ethics and an attitude of compassion towards all beings. This same non-duality, considered in ontological terms, implies the emptiness of all phenomena as no one phenomena can be considered intrinsically different from any other. It follows that all phenomena are empty. This emptiness is not the same as nihilism. Nihilism implies a belief in the absolute nothingness of phenomena that is as absolute as the egocentric belief in the permanence of self. Nihilism and absolutism are poles of the same duality.

In Phase One of this research the initial task of exploring the suffering that the experience of CFS represents is tackled. It requires the remainder of the research to present an interpretation of this suffering. Each of these stages of the research find resonance with the Prasangika approach to suffering, however, the definition of suffering this tradition offers is brought to bear on the experience of CFS only in the interpretation of the experience presented in the Discussion chapter. This definition of suffering was not used to direct the interview process, the semiotic interpretation of the subjects’ words or the initial enactive interpretation of the semiotic analysis. The Mahayana Buddhist doctrine of no-self, that underpins the Prasangika-Madhyamika definition of suffering is discussed in more detail in section 4.7. This doctrine is utilised in the enactive interpretation of the semiotic analysis of the research interviews.

3.6 Conclusion

The research problematic has been outlined in this chapter: the exploration and interpretation of the experience of CFS as a form of suffering, an illness process and a psychosomatic phenomenon. Studying experience of any sort requires an approach to consciousness. Chapter 4

presents the aspects of the enactive approach to cognitive science that the research requires in order to develop an adequate approach to the psychosomatic and analyse the exploration of the experience. Enaction also provides the research with a lens through which to consider consciousness. This will be further employed in the research discussion.

4. An Enactive Architecture of Conscious Experience

To me, the chance of surviving with dignity on this planet hinges on the acquisition of a new mind. This new mind must be wrought, among other things, from a radically different epistemology which will inform relevant actions. ... a world view beyond the split between us and it, where knowledge and its world are as inseparable as the inseparability between perception and action. In this middle-way view, what we do is what we know, and ours is but one of many possible worlds. It is not a mirroring of the world, but the *laying down*⁸ of a world, with no warfare between self and other. (Varela 1987, pp.49 and 62)

4.1 Introduction

This research considers a phenomenon of conscious experience from the perspective of the subject: the experience of suffering from and recovering from the psychosomatic illness CFS. The research, therefore, requires an architecture of consciousness that acknowledges the phenomenality or subjectivity of experience: one that does not objectify experience.

The initial exploration of the CFS experience, presented in Phase One of the research, reveals the importance of the self to this experience. The approach to consciousness that is enlisted in the analysis of this exploration, therefore, needs to provide an adequate model of the self and processes of self-transformation. To begin to become ill or to recover from illness involves self-transformations.

For reasons outlined in the previous chapter, the research also requires an embodied approach.

The enactive analysis of the semiotic analysis of the CFS experience and the research discussion reveal the importance of the role of action situated in the world to this experience. Enaction as a theory of embodied action meets these needs.

The architecture of consciousness that this research enlists to meet these requirements, known as enaction was first articulated in *The Embodied Mind* (Varela, Thompson, and Rosch 1991). This foundation text presents the enactive critique of cognitivism and develops the enactive approach to consciousness and the science of mind. There are a number of authors who have taken the enactive approach, and its critique of cognitivism, as a basis for research in a number of areas of first-person phenomenological research, neurology and cognitive science (Gallagher and Varela 2003; Le Van Quyen and Petitmiengin 2002; Lutz 2002a; Lutz, Dunne, and Davidson forthcoming, 2007; Lutz et al. 2004; Lutz et al. 2002b; Martinerie et al. 1998).

Enaction is a synthesis of aspects of cognitive science, phenomenology and Mahayana Buddhism. Since there are few secondary sources on the enactive approach, the sections of this chapter present the aspects of enaction, with their necessary background, required by this

⁸ Unless otherwise stated, all italics or emphasis in quotations are original to the author quoted.

research is founded. For an alternative presentation, see Rudrauf, Lutz et al (2003) and Torrance (2005).

Torrance (2005) proposes two approaches to enaction, both of which are based on the foundational work, *The Embodied Mind* (Varela, Thompson, and Rosch 1991). The manner in which this research engages each of these approaches is detailed in Section 4.2.

Enaction has been shaped by a consideration of the shortfalls of mainstream cognitive science, coined cognitivism by Varela, Thompson and Rosch (1991). Cognitivism does not provide an adequate model of consciousness for the present research as it is a powerful instantiation of the mind/body dichotomy. Nonetheless, the cognitivist model has important implications for any consideration of the architecture of consciousness, such as the assertion of the disunity of the self and the existence of symbolic representation. The contributions that cognitivism has to make to the enactive approach, as well as its limitations, are discussed in section 4.3. This section is necessary background to sections 4.7, 4.8, and 4.12.

An important focus within the enactive approach is the use of experiential or phenomenal data. Early Western thought towards a method for the study of immediate experience is discussed in section 4.4, contributes to the discussion of duality in section 4.6, and is referred to again in chapter 5. Mindful awareness⁹, as a method for the study of experience that moves away from disembodied reflection, is pragmatic and acknowledges transformation, is presented in section 4.5 and further developed in chapters 6 and 7, particularly sections 6.3 and 7.6. The embodied reflection of mindfulness is congruent with the aim of this research to consider the experience of CFS through a non-dual lens. How mindfulness can be brought to bear on the problem of Cartesian dualism is discussed in section 4.6. Mindfulness also contributes to an enactive understanding of the ontological basis of experience as groundless which is explored in section 4.13.

A synopsis of the argument for no-self is presented in section 4.7. This argument establishes the ego-self as an illusion that is no more than a disposition of mind. Other tools considered in this section include the five aggregates that constitute the psychophysical complex. The proof of no-self supports the cognitivist claim for the disunity of self and it also provides an understanding of self-transformation. This ability to conceptualise self-transformation is employed in the enactive analyses of the semiotic analysis presented in the analysis chapters (chapters 9, 10, and 11). The proof of no-self also contributes towards treatment suggestions put

⁹ “The practice of recognizing emptiness in every moment is known as the practice of mindfulness/awareness or samatha-vispasnya. Essentially a radical not-doing, it is traditionally understood as a universal practice, but despite having been refined and explored for 2500 years by over half the world, it was never discovered independently in the West. Instead of a space for the human in the analyst’s studio required by psychoanalysis, samatha-vipasnya creates the space through non-action, which includes nonresponse to language” (Varela 1992, p.66).

forward in chapter 12. The material in this section amplifies and clarifies the basis of the Prasangika definition of suffering which was introduced in the previous chapter and is revisited in the research discussion. The aggregates and the psychophysical complex are used in the enactive analysis mentioned above, they are also enlisted in the discussion of action presented in chapter 12.

Enaction is informed by the emergent approach to cognition. A consideration of cognition as emergent is necessary to the enactive discussion of the architecture of consciousness as enaction considers cognition and consciousness to be codependently arising. Considered in section 4.8, emergence provides an explanation for how a system's neuronal structure relates to its history and how the meaning of symbolic representations are derived from the patterns of activity that the organism undergoes. In other words, in emergent terms, meaning is derived from action. By allowing representation to be approximate, emergence explains how a system can have experience, a history and an ability to adapt. The connection between action and meaning forged by emergence is of central importance to the enactive analysis of the semiotic analysis and research discussion.

Returning to the contributions from mindfulness to enaction at the level of conscious experience, the 'Wheel of Life' or 'Wheel of Karma' provides an explanation for the phenomenal causality of experience and action. Discussed in section 4.9, this analysis also provides an explanation for the experience of self-coherence. The 'Wheel of Karma' is used in the enactive analysis of the semiotic analysis and in the thesis discussion.

The Buddhist analysis of the most basic elements of experience is presented in section 4.10. What emergence (section 4.8) offers basic element analysis is the possibility of viewing the basic elements of experience as emergent. Further, in combination with the Buddhist analysis of the mental factors, discussed in section 4.11, it becomes clear that consciousness is also emergent. The role of the first mental factor, contact, as both cause and effect is described in section 4.11 and it is argued that contact represents an early description of the logic of self-reference and the notion of circular causality or feedback and feedforward that forms the basis of the scientific concept of emergence. Basic element analysis, the mental factors and contact, in particular, are all elements of the enactive architecture of consciousness that are enlisted in the enactive analysis of the semiotic analysis. Contact is particularly important to the analysis of 'energy' presented in chapter 11. Further, these elements are key to the development of the model of action discussed in chapter 12.

Building on emergence, the concept of operational closure is discussed in section 4.12. To illustrate the ontological importance of operational closure, representation is revisited and a

distinction between weak and strong representation is presented. This distinction is crucial to the justification of the cluster analysis applied in the research method. Operational closure describes the process in consciousness that provides a system with its ability to modify itself. This is necessary to creativity and transformation within consciousness and is most clearly illustrated by ‘common sense’, presented in section 4.13. The discussion of common sense shows how a Buddhist analysis of the subject/object dichotomy suggests a middle way between Idealism and Realism. This middle way is put into practice through the concept of intersubjectivity. Intersubjectivity is a key component of the theoretical background to the research methodology. To consider illness as a process, particularly one that involves recovery, an understanding of transformation is necessary. This is utilised in the enactive analysis of the semiotic analysis and supports a number of treatment suggestions addressed in the thesis discussion. Operational closure and intersubjectivity are necessary to the model of action discussed in chapter 12.

Enaction suggests that meaning is derived from action and action is constrained by the meanings the organism derives from experience, including its experience of the environment. In other words, there can be no experience without action, action and experience are not categorically distinct, they co-arise. In effect, to have an experience is an action. What this requires is a process of viable structural coupling between the organism and its environment and an understanding of how the objects of ‘common sense’ ‘know-how’ are formed. The objects of ‘common sense’ ‘know-how’ do not have clearly independent boundaries from the subject, rather, they are formed in relation to the subject’s past experiences and actions. These points and the role of intentionality and proprioception or sensorimotor capacities are discussed in section 4.14, Enaction. The model of action discussed in chapter 12 draws directly on Enaction.

In section 4.15, the enactive model of the ontologically fragile self as a complex entity is presented. This model of self draws on the capacity to ‘let go’ as a means to invoke the process of continually creating and recreating itself from multiple levels of emergence. Letting go is further explored in section 5.5, is utilised in the research method as a component of epoche and contributes towards the enactive analysis of the CFS experience. Such an enactively emergent self is a powerful model of action and presence within the world. The ontologically fragile self considerably illuminates the semiotic analysis of the ‘recovered self’ presented by the recovered interviewees, is potentially key to an understanding of the process of recovery and leads to a number of treatment suggestions. This model of the self and the enactive architecture of consciousness provide the ‘new mind’ Varela refers to in the epigraph to this chapter.

4.2 Locating the Research: Two Approaches to Enaction

Torrance (2005) reviews how the enactive project, as established in the *The Embodied Mind* (1991), has, since, been developed and applied and distinguishes two enactive approaches. The first, utilised by this research, is concerned with a broad approach to the nature of mind, whereas, the second is more specifically concerned with the nature of perception. This research engages only briefly with the second enactive approach. In the discussion chapter, a number of suggestions pertaining to future research require this more specific approach.

Torrance states:

A key underlying notion in the enactive approach, conceived broadly, is that living is itself a cognitive process – a process whereby a living being creates and maintains its own domain of meaningfulness, in generating and maintaining its own self-identity as an embodied organism. (Torrance 2005 p.359)

The insight that we create and maintain our own domain of meaningfulness as embodied organisms crucially retains the body as a source of meaning. This provides a constructive base for the consideration of the psychosomatic and is compatible with Gendlin's theory of meaning. Torrance comments: "one experiences one's body both as object (for instance as seen in a mirror) and, pre-reflectively, as subject. Any *scientific* account of the human organism must embrace both these complementary perspectives" (Torrance 2005 p.364). The method employed in this research engages with the subjectivity of CFS. The CFS body as object is considered by existing research from biomedicine and neurology. The research discussion enlists this literature to provide further explanation of the experience of CFS as it has been formalised in the research analysis. Likewise, the formalised experience sheds light on the biomedical and neurological findings discussed.

4.3 Cognitivism and the Self

Varela, Thompson and Rosch (1991, p.38) locate the origins of cognitive science in the era of cybernetics. From cybernetics, cognitive science inherited the project of understanding the nervous system through mathematical logic, the development of information processing machines such as the computer, the development of the metadiscipline of systems theory, information theory and the first attempts at constructing self-organising systems. Cybernetics as it was represented by McCulloch (1965) was an empirical, mathematical and philosophical endeavour that nonetheless attempted to understand mental phenomena in explicitly mechanistic and mathematical terms.

Later cybernetics tended to overemphasise the notion that the mind could be represented as logical calculation at the expense of other aspects of the discipline (Varela, Thompson, and

Rosch 1991, p.39). Consequently, to the detriment of contributions from the biological and social sciences, what became mainstream cognitive science, referred to by Varela, Thompson and Rosch (1991) as cognitivism, adopted the notion of mind as a process of logical calculation with its central tenet that “cognition so resembles computation in its essential characteristics that cognition can actually be defined as computations of symbolic representations” (Varela, Thompson, and Rosch 1991, p.40). From this assumption, cognitivism constructs cognition as actions based on representations that are physically manifest in the brain through a system of symbols. The cognitivist project becomes to show how representational states are possible and how they cause behaviour. The notion of symbolic computation implies that symbols, such as those manipulated by the brain, have both physical reality and semantic value. Computation involves the manipulation of symbols in ways that are constrained by their semantic values. Taking the computer as an example, for instance, the semantic values of the symbols under manipulation are encoded in the operational structure of the program. For cognitivism, this acts as a model for all cognition and shows how “intelligence and intentionality (semantics) are physically and mechanically possible” (Varela, Thompson, and Rosch 1991, p.41).

The enactive approach recognises that minds employ symbolic representation but it does not assume that symbolic representation is the only cognitive mode of functioning. Further, enaction does not accept a number of the outcomes of the cognitivist approach to representation. Firstly, cognitivism implies a strong link between syntax and semantics and secondly, cognitivism implies that cognition involves an irreducible symbolic domain (Varela, Thompson, and Rosch 1991, p.41; Noë and O'Regan 2002a). The relationship between semantics and syntax here is problematic. In the example of a computer, it is clear that the semantic value of its computations comes from the programmer. It is not so clear that all the semantic values that exist in human language could be so easily mirrored in syntax. Nor is it clear how they would initially come to have their ascribed values (Varela, Thompson, and Rosch 1991, p.42). The approach Varela, Thompson and Rosch (1991 p.98) refer to as emergence begins to attend to this first problem.

When Freud postulated the existence of the unconscious, he introduced the idea of a divided self, in the sense that the self became several selves. Freud accepted the notion that the unconscious could involve a symbolic system which was distinct from that employed by conscious awareness. Nonetheless, Freud insisted that the contents of the unconscious could be made known fully to conscious awareness. Cognitivism is making a considerably stronger claim: “(1) cognitivism postulates mental or cognitive processes of which we are not only unaware but of which we cannot be aware, and (2) cognitivism is thereby led to embrace the idea that the self

or cognizing subject is fundamentally fragmented or nonunified” (Varela, Thompson, and Rosch 1991, p.48). In effect, cognitivism as a science of mind claims to explain cognition through cognitive structures and processes to which we have no recourse through conscious awareness, introspection or through disciplined practices such as psychoanalysis. Consequently, cognitivism raises the question of whether there is any necessary connection between cognition and conscious awareness or, indeed, body and mind. For cognitivism, “cognition and intentionality (representation) are the inseparable pair, not cognition and consciousness” (Varela, Thompson, and Rosch 1991, p.50). This implies that cognition can exist entirely independently of consciousness. Given that consciousness is considered a central feature of the self and that under cognitivism consciousness is not necessary for cognition, it follows that cognition is possible without self. This position is clearly in contradiction to the everyday experience of self coherence. Although cognitivism asserts the existence of cognition, it provides no account of consciousness and questions the existence of the self as we consciously experience it. The enactive approach accepts the cognitivist claim to a nonunified self. Rather than reject the experience of self coherence, however, the enactive approach is to search for a model of consciousness that explains this experience.

Varela, Thompson and Rosch (1991, pp.51-56) review the work of one cognitivist, Ray Jackendoff, who has attempted to tackle these issues in his examination of the relationships between consciousness, the mind (cognition) and the self. Jackendoff’s work focuses on the problematic relationship between the realm of cognition, of which we are unaware or unconscious, and consciousness. Jackendoff refers to the unconscious realm of cognition as the computational mind and the realm of consciousness as the phenomenological mind and identifies what he calls the *mind-mind* problem.

The upshot is that psychology now has not two domains to worry about, the brain and the mind, but three: the brain, the computational mind, and the phenomenological mind. Consequently, Descartes’ formulation of the mind/body problem is split into two separate issues. The “phenomenological mind/body problem” ... is, How can a brain have experiences? The “computational mind/body problem” is, How can a brain accomplish reasoning? In addition, we have the *mind-mind* problem, namely, What is the relationship between computational states and experience? (Jackendoff 1987, p.20 in Varela, Thompson, and Rosch 1991, p.52)

To address this *mind-mind* problem, Jackendoff claims consciousness, or the phenomenological mind, is an externalisation or projection of a subset of operations of the computational mind. In other words, experience is the result of a projection of the computational mind. These projections correspond to an intermediate level of representation, one that is less peripheral than sensory input but less central than complex thought patterns. Consciousness, or the phenomenological mind, therefore, is generated by the computational mind.

Jackendoff recognises what follows from this: that the phenomenological mind constrains the computational mind. He claims that if empirical experiential evidence is brought to bear on the model of the computational mind and this model is found to lack adequate distinctions to explain such experiential phenomena, then the model of the computational mind must be expanded until it does encompass those experiential phenomena.

To explain cognition, we turn to investigate our structure-understood in the present context as our computational mind. But since it is also cognition as experience that we wish to explain, we must turn back and attend to the kinds of distinctions we draw in experience-the phenomenological mind. (Varela, Thompson, and Rosch 1991, p.54)

What then of competing accounts of experiential phenomena? To this question, Jackendoff offers only “the hope that disagreements about phenomenology can be settled in an atmosphere of mutual trust” (Jackendoff 1987, p.275 in Varela, Thompson, and Rosch 1991, p.54). This statement demonstrates how a tradition of Western thought that “neither provides a critique of mindless phenomenologising nor provides any method, other than hit or miss hand waving, to investigate the phenomenological mind” (Varela, Thompson, and Rosch 1991, p.55) has been largely unable to support Jackendoff’s approach. Cognition cannot be understood in isolation from experience. This highlights the need for a pragmatic disciplined method for understanding experience in order to understand either cognition or experience. In other words, uncovering the relevant phenomenological distinctions with which to complete a model of the computational mind requires a disciplined means of approaching the distinctions made by the phenomenological mind.

By introducing an intermediate layer to representation, Jackendoff’s investigations of the relations between consciousness, mind and self have brought him not only to the conclusion of the nonunified self but further to the disunity of consciousness itself (Varela, Thompson, and Rosch 1991, p.56). Jackendoff’s investigation was motivated by the *mind-mind* problem and unlike mainstream cognitivism, he has considered the phenomenological evidence for this disunity (Varela, Thompson, and Rosch 1991, p.55). By treating the phenomenological mind as a projection of the computational mind, however, Jackendoff is led to conclude that consciousness has no causal efficacy. He holds that all causality exists at the level of the computational mind only and concludes that consciousness “is not good for anything” (Jackendoff 1987, p.26 in Varela, Thompson, and Rosch 1991, p.56). It would appear that Jackendoff has reduced experience to an epiphenomenon. This highlights the need to find a middle way between a complete rejection and an unquestioned acceptance of experience. In contrast to Jackendoff’s cognitivism, enaction and its corresponding neurophenomenological methodology enlist experience and propose a relationship of mutual generation and constraint between the

computational and the phenomenological or biological and psychological as a central tenet. Enaction attempts to understand how the meanings ascribed to symbolic representations are generated and how the organism relates to its environment through experience. Similarly, Gendlin (1962) investigates the generation of meaning in relation to experience and the symbolic domain.

4.4 Experience and Western Thought

Varela, Thompson and Rosch (1991) identify phenomenology as the principal tradition within Western thought that examines experience. Husserl's initial attempt to study experience through an examination of the structure of intentionality is an important example of such an examination. Husserl suggested that through introspection one could identify the fundamental essences of intuition without any recourse to the empirical world. It would then be possible to show how experiences of the empirical world were generated from these essences. In so doing, Husserl took several important steps: "he claimed that to understand cognition, we cannot take the world naïvely but must see it instead as having the mark of our own structure. Husserl also took the second step, at least partially, in realizing that that structure (the first step) was something that he was cognizing with his own mind" (Varela, Thompson, and Rosch 1991, p.16). With these assertions, Husserl deliberately stepped out of the dominant scientific objectivism of his time. He argued that all theoretical and scientific activity presupposed the life-world as a given and defined the phenomenological project as an attempt to recover experience by uncovering the relationships between consciousness, experience and the life-world (Varela, Thompson, and Rosch 1991, p.17). This pure phenomenology, Husserl believed, would expand the domain of science and philosophy such that experience could be studied rather than presupposed.

For Husserl, however, the exercise of forming the essences of intuition was contained within the mind without any prior recourse to experience (Varela, Thompson, and Rosch 1991, p.16). As such, his phenomenology remained purely theoretical and consequently suffered from the same disconnection from the life-world as the philosophy and science he was attempting to expand. His approach lacked an empirical pragmatic dimension (Varela, Thompson, and Rosch 1991, p.19).

The irony of Husserl's procedure, then, is that although he claimed to be turning philosophy toward a direct facing of experience, he was actually ignoring both the consensual aspect and the direct embodied aspect of experience. (Varela, Thompson, and Rosch 1991, p.17)

This criticism, Varela, Thompson and Rosch comment, can also be mounted against Heidegger's existential phenomenology and Merleau-Ponty's phenomenology of lived experience (1991, p.19). For this reason, none of these phenomenologies have bridged the gap between science and

experience. Heidegger and Merleau-Ponty identify the pragmatic, consensual and embodied context of experience but they do this only theoretically. Merleau-Ponty recognised this difficulty when he offered the critique of both science and phenomenology as theoretical activities that examine embodied experience always after the fact. Varela, Thompson and Rosch (1991, p.20) extend this claim to include the entire field of Western philosophy as rational theoretical reflection. On this note, they turn to psychoanalysis as the principal Western tradition that studies un-reason. Like Western philosophy and science, however, psychoanalysis also studies experience after the fact and from within the individual's conceptual framework. It lacks a method with which to study the immediacy of experience. Before an architecture of consciousness can be established and refined, what is required is "an examination of human experience in both its reflective and its immediate, lived aspects" (Varela, Thompson, and Rosch 1991, p.21).

4.5 Mindful Awareness as an Embodied Method for the Study of Experience

Varela, Thompson and Rosch (1991, p.21) turn to the philosophical traditions of India for a disciplined method with which to study the reflective and immediate aspects of lived experience. Within these traditions, thought has always remained yoked or tied to specific pragmatic methods of investigation, including the investigation of the immediacy of experience (Varela, Thompson, and Rosch 1991, p.22). Varela, Thompson and Rosch (1991) propose that the Buddhist tradition of mindful awareness, in particular, can provide both the method required and significant insights into the architecture of consciousness.

The doctrines of no-self and non-dualism of the Madhyamika school are central to the practice of mindful awareness. Varela, Thompson and Rosch (1991, p.21) consider that the doctrine of no-self can contribute to the understanding within cognitive science of the nonunified self and the doctrine of non-dualism can be juxtaposed to Merleau-Ponty's *entre-deux* to provide a middle way between Realism and Idealism.

Mindfulness means that the mind is present in embodied everyday experience; mindfulness techniques are designed to lead the mind back from its theories and preoccupations, back from the abstract attitude, to the situation of one's experience itself. Furthermore, and equally of interest in the modern context, the descriptions and commentaries on mind that grew out of this tradition never became divorced from living pragmatics: they were intended to inform an individual as to how to handle his mind in personal and interpersonal situations, and they both informed and became embodied in the structure of communities. (Varela, Thompson, and Rosch 1991, p.22)

Through the practice of mindful awareness, the mind becomes an instrument for knowing itself. Initially, the practitioner begins to realise the extent to which the mind wanders and the extent to which the mind and the body are not coordinated (Varela, Thompson, and Rosch 1991, p.24).

These observations become the practitioners' measure of their own lack of presence (Varela, Thompson, and Rosch 1991, p.25).

Varela, Thompson and Rosch describe two stages of practice: *shamatha*, the calming or taming of the mind and *vipashyana*, the development of insight (Varela, Thompson, and Rosch 1991, p.24)¹⁰. Through formal sessions of sitting meditation, the practitioner begins to identify the difference between his or her mind when it is present and when it is not. This understanding is then extended into daily life.

Thus the first great discovery of mindfulness meditation tends to be not some encompassing insight into the nature of mind but the piercing realization of just how disconnected humans normally are from their very experience. ... The meditator now discovers that the abstract attitude which Heidegger and Merleau-Ponty ascribe to science and philosophy is actually the attitude of everyday life when one is not mindful. This abstract attitude is the spacesuit, the padding of habits and preconceptions, the armor with which one habitually distances oneself from one's experience. (Varela, Thompson, and Rosch 1991, p.25)

Mindful awareness as a pragmatic study of the nature of experience demonstrates that the dissociation of mind from body and awareness from experience can be changed. As the practitioner becomes less habitually lost in the mind's restlessness and wandering, the practitioner begins to experience a greater sense of spaciousness, perspective and awareness. The process of uncovering the natural state of mind as present and embodied, through the letting go of illusions and habitual grasping, begins the discovery of *prajna*, that is, the discovery of wisdom or maturity.

Prajna as an embodied means of investigating experience potentially transforms Western understandings of knowledge, reflection and experience. Knowledge in the sense of *prajna* is not knowledge *about* something. "There is no abstract knower of an experience that is separate from the experience itself" (Varela, Thompson, and Rosch 1991, p.26). Likewise, reflection is not an abstract disembodied enterprise. Reflection is a form of embodied experience.

By *embodied*, we mean reflection in which body and mind have been brought together. What this formulation intends to convey is that reflection is not just *on* experience, but reflection *is* a form of experience itself – and that reflective form of experience can be performed with mindful awareness. (Varela, Thompson, and Rosch 1991, p.27)

Embodied reflection is open-ended: it promotes awareness and enables the practitioner to initiate changes (transformation) within their current representation of the lived world (Varela,

¹⁰ *Shamatha* (Sanskrit) *shine* (Tibetan) Meditation for stilling and calming the mind. Traditionally, a concentration technique. It is rarely practiced in its most pure, radical form.

Vipassana (Pali) The meditation technique practiced today in the Theravada tradition of Buddhism. Its purpose is both to calm the mind and arouse insight. The general technique is for the mind to remain mindfully with its object, whatever that object may be. There are many specific techniques.

Vipashyana (Sanskrit) *lhagthong* (Tibetan) Insight. The term is used in at least two major senses: 1. Specific techniques used within meditation for examining the calmed mind to obtain insight into its nature. ... 2. The panoramic awareness in meditation or daily life that enables the practitioner to see with a sense of mature wisdom whatever is occurring. (Varela, Thompson, and Rosch 1991, p.255)

Thompson, and Rosch 1991, pp.27-31). This process always maintains its reference point in the knower (Varela, Thompson, and Rosch 1991, p.30). It avoids the ‘disembodied view from nowhere’ that is characteristic of objectivist science, that “disembodied view from nowhere that leads to having a view from a very specific, theoretically confined, preconceptually entrapped somewhere” (Varela, Thompson, and Rosch 1991, p.27). Unlike phenomenology, which has remained confined between reflection *on* experience and subjectivism, mindful awareness succeeds in creating a middle way. This research employs a methodology that is underpinned by mindful awareness.

It could be argued that mindfulness is simply a form of introspection and introspection has failed to provide any basis for experimental psychology. From the perspective of mindfulness, however, introspection is no more than disembodied thinking about thought. Mindfulness aims specifically at cutting through this introspective attitude. Alternatively, it could be argued that mindfulness cannot offer a means of observing everyday experience as it requires the practitioner to inhabit a mode of being that is not everyday. From the perspective of mindfulness, however, this does not make sense since to raise this objection means to assume that one can step out of everyday experience. It requires that we invent an independent abstract mode. Mindfulness is precisely the antidote to such an abstract mode. One has to be in a mindful state to become aware that there is such a thing as an everyday experience of being in the world.

What mindfulness disrupts is mindlessness – that is, being mindlessly involved without realizing that that is what one is doing. It is only in this sense that the observation changes what is being observed, and that is part of what we mean by open-ended reflection. (Varela, Thompson, and Rosch 1991, pp.32-33)

The fact that mindfulness acknowledges the human capacity to transform is particularly apt for the present research, since this research considers the transformations of suffering from and recovering from CFS.

4.6 Reassessing Cartesian Dualism with Mindful Awareness

A central aim of this research is to consider the experience of CFS, a psychosomatic illness, through a theoretical and methodological lens that avoids imposing the mind/body dichotomy. Embodied mindfulness provides the required ontological and methodological focus.

When the pragmatics of mindful awareness is brought to bear on the theoretical problem of the mind/body dichotomy, this problem is transformed. Starting from the observation that the mind and the body can become dissociated and can be brought together, the practitioner acknowledges that the relationship between the mind and the body is not fixed, it is open to change. Western philosophy does not deny this insight but rather fails to acknowledge it.

In summary it is because reflection in our culture has been severed from its bodily life that the mind/body problem has become a central topic for abstract reflection. Cartesian dualism is not so much one competing solution as it is the formulation of this problem. Reflection is taken to be distinctively mental, and so the problem arises of how it could ever be linked to the bodily life. ... From the standpoint of a mindful, open-ended reflection the mind/body question need not be, What is the ontological relation between the body and mind, regardless of anyone's experience? – but rather, What are the relations of body and mind in actual experience (the mindfulness aspect), and how do these relations develop, what forms can they take (the open-ended aspect)? (Varela, Thompson, and Rosch 1991, p.30)

In other words, it is because reflection has become disembodied (considered distinctly mental) that the mind/body dichotomy arises in the first place. From this perspective, Cartesian dualism is not a possible answer to a problem that experience demonstrates need not arise, but a problem in itself. If reflection on the mind/body dualism starts from the embodied experience that the mind and body can be in different states of relation, then it can progress to the question of what this relation is in embodied experience and how this relation can be transformed. A body without a mind is merely a collection of raw materials, and a mind without a body does not exist. Both mind and body are emergent aspects of an organism.

Achieving a state of embodied reflection requires effort, but not in the sense of the effort required to acquire something new, rather, it is the effort involved in unlearning habitual patterns that impede the practitioner from recognising that naturally the mind and the body are coordinated, by virtue of being two aspects of a single organism rather than having any separate existence. If the reflection mindfulness brings to bear on the mind/body problem is always embodied within the asker and mindful of the process of asking, then the disembodied question “what is mind?” does not arise (Varela, Thompson, and Rosch 1991, p.30). What follows from this position is the assumption that consciousness is embodied and that an embodied architecture of consciousness will need to reflect this fact. This approach therefore actively avoids engaging mind/body dualism.

Torrance (2005) highlights the importance of the enactive contribution to debates surrounding the Cartesian anxiety. He also discusses the middle way between absolutism and nihilism that was proposed in *The Embodied Mind* and has been developed in later work. The argument for this middle way is presented in section 4.13 below. As Torrance comments, this middle way was established on the basis of Varela and Maturana's notion of autopoiesis, the ‘entre-deux’ of Merleau-Ponty, and the “‘middle way’ of the Madhyamika tradition of Buddhism, which asserts the ‘groundlessness’ of both the outer world and the inner world of the ego” (Torrance 2005 p.359-60).

What this middle way offers is a means by which the science of cognition can be used as a basis to a science of consciousness (Torrance 2005). Undoubtedly an important contribution to

these disciplines, this is also an important aspect of the enactive approach for the present research. In order to study a psychosomatic experience it is necessary to have a science of consciousness that is embodied.

Not only does such an approach allow for the disciplined scientific investigation of conscious experience, one that allows mind and body to function equally as sources of meaning, it also allows “cognition and experiential consciousness ... to be best seen as two parts of the same process – that of the lived, embodied action of the organism within its world” (Torrance 2005 p.361). This supports the possibility of research that engages a circulation between first-person subjectivity and third-person objective approaches. I would argue that this is particularly necessary for the consideration of the psychosomatic. Boldly put, we need to get the hard problem of consciousness out of the way in order to get started in researching psychosomatic phenomena. Appendix L presents a summary of the hard problem of consciousness and its relevance to this research. Psychosomatic phenomena require the ability to comprehend the circulation between first and third person evidence, just as they require engagement with both psyche and soma. Ideally comprehensive studies of psychosomatic phenomena would engage both the ‘neuro’ and the ‘phenomenal’ directly and in mutual constraint. This theme will be developed further in section 5.2.

4.7 No-Self, the Aggregates and the Wheel of Karma

Mindful awareness contributes towards an understanding of the everyday phenomenon of self-coherence. Varela, Thompson and Rosch (1991, p.59) comment:

... most of us are convinced of our identities: we have a personality, memories and recollections, and plans and anticipations, which seem to come together in a coherent point of view, a center from which we survey the world, the ground on which we stand. How could such a point of view be possible if it were not rooted in a single, independent, truly existing self or ego? (Varela, Thompson, and Rosch 1991, p.59)

Not only how, but that such a permanent, unchanging ground or self could exist is paradoxical given that the experiences such a permanent ego-self undergoes are always impermanent and context dependent. Western reflective traditions have responded to this paradox by challenging the naïve sense of a fixed and independent self, either by positing a transcendental self or by ignoring this naïve self. The Buddhist doctrines of no-self and nondualism confront this contradiction directly. By applying mindful awareness, it is possible to observe that both experience and experiencer or perceiver and perceived are impermanent. The experience of the impermanence of the experiencer, or self, is referred to as selflessness or egolessness. The mind’s grasping after or construction of a permanent self, or ground, and its attempts to escape from selflessness are observed to be the source of *dukkha* or suffering. To examine the source of

dukkha, the meditator develops “a strong and stable insight and inquisitiveness into the moment to moment arising of mind ... the search for how the self arises is thus a way of asking, “what and where is mind?” in a direct and personal way” (Varela, Thompson, and Rosch 1991, p.61).

Within the *Abhidharma* texts¹¹ are several systems of categories for conscious phenomena that the practitioner can sift through in an exhaustive examination of the arising of the experience of self. These systems of categorisation contribute towards an understanding of the structure of consciousness. One set of categories used within all the schools of Buddhism is called the five aggregates. Taken together, the five aggregates “constitute the psychophysical complex that makes up a person and that makes up each moment of experience” (Varela, Thompson, and Rosch 1991, p.64). What follows is a brief synopsis of this process of searching within each of the aggregates for anything that resembles our sense of a permanent ego-self. The five aggregates are central to the enactive analysis of the semiotic analysis of CFS developed in this research.

The first of the five aggregates, or heaps, is that of ‘form’. Form prompts the question: “Is our body our self?” (Varela, Thompson, and Rosch 1991, p.65). As with Merleau-Ponty, to ask this question from the perspective of mindfulness is to consider matter as it is experienced: situated and embodied. Assuming that the form of the body can be reduced to the content of the cells the search for the self within form considers whether the self can be found within the cells. Cells are completely replaced every seven years so they cannot contain a permanent self. The question remains: is it the pattern that the cells inhabit that makes up the ego-self? Again this pattern cannot be the self as it would change according to our definition of identity.

It all depends on what your criteria of identity are. ... For something to change there must also be some kind of implicit permanence that acts as a reference point in judging that a change has occurred. So the answer to the quandary is both yes and no, and the details of any specific yes or no answer will depend on one’s criteria of identity in the given situation. (Varela, Thompson, and Rosch 1991, pp.65-66)

Clearly, this does not provide a permanent sense of self. Furthermore, positing the pattern of the cells as the self does not give us the self itself as that would require knowing what this pattern was. Varela considers most convincing the speculation that after a total body transplant the self could still be recognisable in the resulting configuration. Clearly, the self does not reside within (bodily) form. At this point, the search turns to the second aggregate ‘feelings or sensations’.

Feelings and sensations are generally considered to affect the self but they are not usually seen as the self as they are fleeting, changing from moment to moment. From an examination of

¹¹ “First elaborated as lists, the *Abhidharma* contains the earlier texts in which Buddhist concepts were developed, and hence was the source of most philosophical developments in Indian Buddhism.” (Dreyfus and Thompson forthcoming, 2007, p.7) *Abhidharma* also refers to “one of the oldest Buddhist traditions, which can be traced back to the first centuries after the Buddha (566-483 BCE)” (Dreyfus and Thompson forthcoming, 2007, p.7).

the second aggregate the question remains: “what/who is it, then, that feelings are affecting?” (Varela, Thompson, and Rosch 1991, p.66). The third aggregate, ‘perceptions/impulses’, connotes the moment of recognition of anything distinct and the impulse to action that this recognition is coupled with. There are said to be three kinds of impulse: anger, desire and delusion or ignoring. Mindfulness suggests that habitually we react with one of these impulses according to whether the distinction perceived is undesirable, desirable or irrelevant to the self. These impulses are also considered to be the roots of the grasping of the ego but not the ego itself. The consideration of the third aggregate leaves the question: “who is this ego who is grasping?” (Varela, Thompson, and Rosch 1991, p.67).

The fourth aggregate, ‘dispositional formations’, refers to habitual patterns such as worry, confidence, avarice and laziness that are constituted by thinking, feeling, acting and perceiving. These habitual patterns make up an individual’s personality. An ego-self cannot derive from such habitual patterns as these change over time. Such habitual patterns do not provide the sense of continuity that is associated with an ego-self.

The last of the aggregates, ‘consciousness’, contains all of the previous aggregates, just as each of the previous aggregates did likewise. *Vijnana*, or consciousness, refers to the “dualistic sense of experience in which there is an experiencer, an object experienced, and a relation (or relations) binding them together” (Varela, Thompson, and Rosch 1991, p.67). The relations that bind consciousness to its object are referred to as mental factors. Five of the mental factors are always present in any moment of consciousness. These include: “*contact* between the mind and its object; a *specific* feeling tone of pleasantness, unpleasantness or neutrality; a *discernment* of the object; an *intention* toward the object; and *attention* to the object. (Varela, Thompson, and Rosch 1991, p.68)” The remaining mental factors, which include all of the dispositions that constitute the fourth aggregate, are not always present and indeed may be mutually exclusive, such as alertness and drowsiness. In sum, the aggregates and mental factors that are present in any moment of consciousness lend that moment its character.

Unlike Husserl’s system of intentionality, the objects of consciousness and the mental factors employed within the Abhidharma’s analysis of consciousness are not representations. Furthermore, *vijnana* is not the only mode of knowing. *Prajna*, or wisdom, provides a route to knowledge that does not invoke the subject/object dichotomy. *Prajna* is not knowledge *about* anything, rather, through an attitude of letting go, “the mind’s natural characteristic of knowing itself and reflecting its own experience can shine forth” (Varela, Thompson, and Rosch 1991, p.26).

Different schools of Buddhism have debated whether the object of consciousness arises simultaneously with the moment of consciousness or whether the object arises first (Varela, Thompson, and Rosch 1991, p.68). Nonetheless, all the schools of Buddhism agree that each moment of consciousness is unique and therefore there is no moment of consciousness and no element of consciousness that contains an ego-self (Varela, Thompson, and Rosch 1991, p.69). The apparent continuity of consciousness, they argue, is an illusion as the relations between moments of consciousness are simply the result of cause and effect (Varela, Thompson, and Rosch 1991, pp.110-116).

If the self cannot be found within any one of the aggregates, can it be found in the sum of the aggregates? This is clearly not the case as the transitory nature of the aggregates means it is not possible to combine them in such a fashion that would result in something lasting, such as an ego-self. It remains to enquire whether an ego-self could be a process or emergent property of the aggregates. There is, however, no experiential evidence for such a formation and neither would this lead to the kind of abstract sense of ego-self we emotionally crave (Varela, Thompson, and Rosch 1991, pp.69-70).

Insofar as the aggregates constitute the psychophysical complex of a person, no ego-self can be found. This examination of the aggregates has supported cognitivism's claim that there is no ego-self. Further, the examination of consciousness as the fifth aggregate suggests that experience is constructed from discrete moments that are linked only through cause and effect and there is evidence for this momentariness of experience within cognitive science (Varela, Thompson, and Rosch 1991, p.72).

Within the literature of 'perceptual framing', experiments in 'perceptual simultaneity' or 'apparent motion' provide examples of momentariness in the functioning of the brain. If two lights are flashed with less than 50 milliseconds between them, the perceiver will claim that these lights were simultaneous. If the lights are flashed at 100 milliseconds or more, the perceiver will claim that the lights were sequential, whereas if the lights are flashed within 50 and 100 milliseconds of each other, the perceiver will claim that a single light has moved from one position to the next. The first and second cases establish the range within which external stimulæ will be perceived as being part of one 'now', one moment. Varela, Thompson and Rosch (1991, p.73) provide more in depth examples from cognitive science¹² showing how a minimum period of 0.15 milliseconds of activity is required for any perception to take place. These minimal percepts and the moving clouds of neuronal activity in the brain that correspond

¹² For a more in-depth discussion of the evidence for the momentariness of experience, see chapter 4 of *The Embodied Mind* (Varela, Thompson, and Rosch 1991, pp.59-81). In this section, I relate only what is required to provide the reader with a sense of the argument.

to them arise and subside in a fashion that seems to correspond to the aggregates and a momentariness to experience.

This neuropsychological perspective is interesting for our purposes because the parsing of experience naturally corresponds to the aggregates of the mindfulness/awareness practitioner. In fact, the phenomenon of parsing is not evident at first glance for either the neuropsychologist or the practitioner. But it can be revealed through a disciplined method of examining experience, such as mindfulness/awareness. (Varela, Thompson, and Rosch 1991, p.77)

Just as mindfulness has been able to corroborate the cognitivist claim of a nonunified self, cognitivism provides experimental evidence for the mindful observation of the momentariness of consciousness.

The proof of no-self from mindfulness also contributes to understanding the ontology of experience. Searching through the aggregates reveals the body, feelings and sensations, perceptions and the elements of the personality: dispositions, volitions and motivations. The aggregates contain the ways in which we can be aware: smelling, tasting, seeing, hearing, and touching and awareness of our own thought processes. The aggregates are full of experience.

Mindful awareness demonstrates that, through the development of *vipashyana* (insight), the practitioner becomes able to expand the experiential space within which the aggregates arise. In so doing, the practitioner becomes able to track the momentary arising of the aggregates and directly perceive their impermanence. This allows the practitioner to recognise that the sense of an ego-self is derived from a habit of clinging to the aggregates which “is itself only another feeling, another disposition of the mind” (Varela, Thompson, and Rosch 1991, p.80). The emptiness of self of the aggregates is, in fact, the necessary grounds for experience.

This arising and subsiding, emergence and decay, is just that emptiness of self in the aggregates of experience. In other words, the very fact that the aggregates are full of experience is the same as the fact that they are empty of self. If there were a solid, really existing self hidden in or behind the aggregates, its unchangeableness would prevent any experience from occurring; its static nature would make the constant arising and subsiding of experience come to a screeching halt. (It is not surprising, therefore, that techniques of meditation that presuppose the existence of such a self proceed by closing off the senses and denying the world of experience.) But that circle of arising and decay of experience turns continuously, and it can do so only because it is empty of a self. (Varela, Thompson, and Rosch 1991, p.80)

It is precisely the absence of an ego-self that allows experience, change and transformation to arise, as any permanent self would be prohibitive.

Cognitivism, with the authority of science, asserts the lack of a fixed self and this potentially leads to the denial of immediate experience, where this experience is contradictory. What cognitivism does not provide is access to the transformative potential of the realisation of no-self.

If science is to continue to maintain its position of de facto authority in a responsible and enlightened manner, then it must enlarge its horizon to include mindful, open-ended analyses of experience, such as the one evoked here. (Varela, Thompson, and Rosch 1991, p.81)

By acknowledging the groundlessness of experience and the illusion of the ego-self, mindfulness provides a basis for understanding self-transformation. The Buddhist analysis of cause and effect, known as the Wheel of Causality, Wheel of Life or Wheel of Karma, extends this to provide an explanation for the causality of mind in action (Varela, Thompson, and Rosch 1991, pp.110-116) and will be discussed in more depth in section 4.9.

4.8 Toward an Inclusive Model for Cognition

Observations, such as the fact that the brain does not function on the basis of rules, does not involve a central processor, and does not store information at precise addresses, prompted concerns in the early years of cybernetics about the efficacy of cognitivism. These concerns have been addressed by the research project known as connectionism or emergence. Emergence hinges on the notion of emergent properties such as those found in self-organising systems. Recent interest in this area has been rekindled by two problems cognitivism has been unable to address. The first is the von Neumann bottleneck¹³ and the second is the fragility of systems where processing is localised rather than distributed. Cognitivism, for instance, cannot explain the resilience and adaptability of the human brain: “the resiliency of the brain to resist damage, or the flexibility of biological cognition to adjust to new environments without compromising all of its competence, is taken for granted by neurobiologists but is nowhere to be seen in the computational paradigm” (Varela, Thompson, and Rosch 1991, p.87).

A typical connectionist model of a network starts with numerous relatively unintelligent units that are connected in ways which give it the global properties that provide the cognitive capacity it requires. “The entire approach depends, then, on introducing the appropriate connections, which is usually done through a rule for the gradual change of connections starting from a fairly arbitrary initial state” (Varela, Thompson, and Rosch 1991, p.87). The most well researched rule for such connectivity is Hebb’s Rule. This rule states that the connectivity of units in the system will correlate with the degree of activity across those connections, thus connections that experience a high degree of activity will remain strongly connected whereas those that do not will be less strongly connected. The significance of this rule is that it provides us with a way of accounting for a system’s relation to its history and functioning through its connective structure: “the system’s connectivity becomes inseparable from its history of

¹³ Within a cognitivist model, symbols are processed through the individual application of sequential rules. Consequently symbols can only undergo one change at a time. Where many rules are required, this creates what is described as the von Neumann bottleneck.

transformation and related to the kind of task defined for the system” (Varela, Thompson, and Rosch 1991, p.87). When the key to a system’s functioning is to be found in the connections between the units spread globally across the system, there is no need for a central processing unit. Varela, Thompson and Rosch (1991) discuss in considerable detail how emergent properties can arise in such a network and show how these global properties, like the connections that form their basis, are transformed according to the experience of the system. Two examples of such transformations are ‘learning by correlation’ and ‘learning by copying’ (Varela, Thompson, and Rosch 1991, p.92).

Returning to the example of the brain, one of the most important laws of connection that seems to hold true with few exceptions is the “law of reciprocity” (Varela, Thompson, and Rosch 1991, p.94). This law implies that if neuron A is connected to neuron B then neuron B will be reciprocally connected to neuron A. For a system as densely interconnected as the brain, the consequence of such a law is that the overall behaviour of the system will, in fact, reflect the activity of all its components: consequence that is true both locally and globally. This coherence exists within the subsections of the brain, for instance, the thalamus or hippocampus, as well as at the level of the connections between the subsections.

As a result the entire system acquires an internal coherence in intricate patterns, even if we cannot say exactly how this occurs. ... In fact, there are many levels of resolution at which such neuronal emergences can be studied, from the level of cellular properties to entire brain regions, each level of detail requiring a different methodology. (Varela, Thompson, and Rosch 1991, p.94)

Emergence explains on the level of neurology how a system’s structure can relate to its history of activity, how a system can adapt and demonstrate resilience and how processing can be distributed in such a way as to allow for reciprocity locally and globally without rules or a central processor.

The question of interest here is whether this model of an emergent property can provide an explanation for or a model of the possible biological basis of properties of a self-organising system such as the aggregates of experience. Taking a sequential view of the arising of the aggregates, for instance, could be compared to taking a sequential view of the functioning of the subsystems of the brain. The first of the aggregates, form, would “have to come first through some preattentive segmentation at the retinal and geniculate level, then sensations and perceptions would arise at the reticular and collicular input, whereas concepts and consciousness would be added at different stages of “higher” brain centers, in areas such as V4, MT, or the inferotemporal cortex” (Varela, Thompson, and Rosch 1991, pp.97-98). Just as the mindful awareness practitioner observes the arising of moments of experience, so too emergent

configurations seem to arise in momentary bundles. In the background, these bundles have required several cycles of activity back and forth between the different subsystems of the brain. In this way, not only does emergence provide a model for the biological basis of the aggregates but the aggregates could be seen as models for self organising emergent processes.

Emergence replaces symbols with complex patterns within dynamic systems.

Cognitivism introduced symbols as a way of bridging the need for a semantic or representational level with the constraint that this level be ultimately physical. ... This separation between form and meaning was the masterstroke that created the cognitivist approach – indeed, it was the same one that created modern logic. But this fundamental move also implies a weakness in addressing cognitive phenomena at a deeper level: How do symbols acquire their meaning? (Varela, Thompson, and Rosch 1991, p.99)

According to cognitivism, a symbol has a physical form but this form has no relation to its meaning. Emergence, in contrast, provides a situated understanding of how meaning arises and how it relates to form (Varela, Thompson, and Rosch 1991, pp.99-100). Meaning is not derived from symbolic representations, rather, it is derived from the patterns of activity that the whole system undergoes. These patterns of activity arise at a subsymbolic level which is closer to the biological and thus much finer grained than the symbolic representations of cognitivism. This explanation of meaning challenges the cognitivist claim to a distinct symbolic level. It provides an understanding of how meaning arises and how a cognitive system can have experience, a history, and the ability to adapt. This does not imply that emergence can completely replace cognitivism. Instead Varela, Thompson and Rosch (1991) propose an inclusive strategy.

In our view, the most interesting relation between subsymbolic emergence and symbolic computation is one of *inclusion*, in which we see symbols as a higher-level description of properties that are ultimately embedded in an underlying distributed system. (Varela, Thompson, and Rosch 1991, p.101)

This inclusive view does not reject the use of symbols as an explanation for functioning at the level of symbolic representation; it expands the taxonomy of cognitive structure to include both the symbolic and the subsymbolic. This implies that symbols are approximate rather than distinct. Symbols do not exist as an isolated level of cognition but rather provide macro-level descriptions of subsymbolic (emergent) relations or units. Their history and governing principles are to be found at a subsymbolic level.

According to Varela, Thompson and Rosch, Minsky and Papert term the units of emergence agencies. These agencies are organised into higher level systems or agencies that coordinate with each other to create a mind that is like a society (Varela, Thompson, and Rosch 1991, pp.105-106). Within this model of mind, Minsky and Papert argue not only for the usefulness of distributed functionality but also for the need for insulation at each level of the system. They observe that it would be difficult for certain kinds of cognitive activities to be

distributed significantly because their activity would interfere with each other. If such activities were insulated within separate agencies, this would make them more efficient within themselves and within the system as a whole. The interactions between such agencies, Minsky and Papert propose, would involve the kind of sequential symbolic processing suggested by cognitivism. This model for cognition is intended to be applied at different levels. What is considered to be an agency at one level may appear as an agent member of an agency from a higher level and vice versa. Likewise, what is considered to be a society will depend on the level considered.

According to Varela, Thompson and Rosch (1991, p.107), although Minsky and Papert's work offers an important contribution to an inclusive model of cognition, one that highlights the challenge of accounting for the need for isolation, Minsky and Papert are not prepared to relinquish the ego-self even though they are aware it runs contrary to their own findings. Varela, Thompson and Rosch (1991, p.107) argue that ultimately their account fails because this perpetuates the rift between science and experience.

4.9 Causality and the Experience of Coherence

Returning to the level of conscious experience, the question remains: if there is no permanent ego-self then how can the experience of self-coherence be explained? Or in other terms: "how and why do the momentary arisings of the elements of experience, the five aggregates and mental factors, follow one another temporally to constitute recurrent patterns?" (Varela, Thompson, and Rosch 1991, p.110). Within Buddhism, two concepts attend to this problem. The first is the Buddha's explanation of causality which explains our *pratityasamutpada*, literally, our "dependence (*pratitya*) upon conditions that are variously originated (*samutpada*)" (Varela, Thompson, and Rosch 1991, p.110). The second is the concept of karma.

Karma in the Buddhist sense does not refer to the idea of a pre-given fate, karma "constitutes a description of psychological causality – of how habits form and continue over time" (Varela, Thompson, and Rosch 1991, pp.110-111). Causality does not refer to external physical laws of cause and effect. Causality is a "causal analysis of direct experience" (Varela, Thompson, and Rosch 1991, p.111). Karma and causality come together in the binding chain of causality or codependent origination, also known as the 'Wheel of Life' or the 'Wheel of Karma'. This twelve linked chain, or wheel, provides an explanation for how the karmic causality of experience works at any level of experience, be it the level of a single moment, a lifetime or several lifetimes. The chain of causality is an examination of phenomenal causality and as such is central to the analysis of action to be employed in this research.

The first link in the chain of experiential causality is the state of ignorance of the lack of an ego-self. Ignorance in this sense also refers to the mistaken beliefs and emotions that arise from a

belief in an ego-self. The second link refers to the volitional actions that arise from a belief in an ego-self. These initial two links are considered the prior conditions for the next eight links, three through ten. The third link is the state of consciousness, that is, the dualistic state of knowing discussed earlier as the fifth aggregate (see section 4.7). Varela, Thompson and Rosch (1991) comment: “remember that consciousness is not the only mode of knowing; one is born into a moment or a lifetime of consciousness, rather than wisdom, because of volitional actions that were based on ignorance” (Varela, Thompson, and Rosch 1991, p.113).

The fourth link, the psychophysical complex, relates to the fact that any moment of consciousness requires coordination between mind and body. Any particular moment of consciousness may have more emphasis at either the physical or mental end of the spectrum of the psychophysical complex but every moment will contain aspects of both ends. Consciousness with a body and a mind leads to consciousness of the six senses: hearing, smelling, tasting, touching, seeing and thinking. These sense consciousnesses constitute the fifth link. Contact between consciousness and its object is represented by the sixth link and the feelings that arise from contact produce the seventh link. This is the point at which awareness of being in the world arises. From feeling comes craving, the eighth link, and from craving comes grasping, the ninth link.

According to Buddhist canon, the first two links represent the past, links three through ten represent the present, and it is action with respect to craving, the eighth link, that determines whether the chain is broken, creating the possibility for change and transformation or whether habitual patterns continue to be perpetuated. Usually craving automatically leads to grasping. Craving involves both the desire for that which is pleasurable and the aversion to what is not pleasurable. Likewise, grasping involves both grasping after what is desired and avoidance of that which is not desired. Grasping automatically initiates the tenth link, becoming. Becoming joins the links that create the present (three through ten) with links eleven and twelve, those that are part of the future. As such becoming “initiates the formation of new patterns that carry over into future situations” (Varela, Thompson, and Rosch 1991, p.114). The eleventh link is birth and usually it is only at this point that the Wheel of Karma is perceived. In birth, a new situation occurs as well as a new mode of being in that situation. The final link in the chain, death, like birth is considered part of the future as the death of the present moment is considered a causal precondition for the arising of the next moment (Varela, Thompson, and Rosch 1991, p.115).

This relentless circle of conditioned human existence is referred to as *samsara*. The continual turning of the wheel of *samsara* leads to unsatisfactoriness and is continually driven by causation unless the individual learns to sever the chain between links eight and nine. The

practitioner learns to do so through the practice of mindful awareness. Once the practitioner has learnt to sever the chain they gain further mindfulness, which can then be brought to bear on the process of severing the chain. In this way, momentum builds.

Within Minsky and Papert's model of the mind as a society, coherence is a product of emergence. Within the mindful awareness tradition, coherence, or the "repetitious patterns of habitual actions emerge from the joint action of the twelve links" (Varela, Thompson, and Rosch 1991, p.116). Within Minsky and Papert's model of emergence, the action of any individual agent can only be defined in relation to the state of the whole system. Likewise, in mindful awareness, the action of any one of the links in the chain of causality depends on the whole chain. In other words, "as in any agency, there is no such thing as a habitual pattern per se except in the operation of the twelve agent motifs, nor is there such a thing as the motifs except in relation to the operation of the entire cyclic system" (Varela, Thompson, and Rosch 1991, p.116).

In Buddhist terms, the individual's formation and accumulation of patterns and trends throughout life becomes the mistaken basis for the perception of an ego-self. The principal sustaining and motivating factor in this process is intention. Intention enters the chain of causality at the link of volitional actions and leaves its trace from that point forth. This results in the accumulation of wholesome and unwholesome habits, responses and tendencies. This is what karma is most often assumed to refer to: "when the term *karma* is used loosely, it refers to these accumulations and their effects. Strictly speaking, though, karma is the very process of intention (volitional action) itself, the main condition in the accumulation of conditioned human experience" (Varela, Thompson, and Rosch 1991, p.116). In effect, karma refers to the assumptions the individual makes about the possibilities of action. The artefacts of consciousness enter into the causes of actions at the third link. Action is the method by which consciousness gains causal efficacy, action is what makes consciousness 'good for something'.

4.10 Basic Element Analysis

Buddhist analyses of experience begin at the level of the most basic unit of conscious experience. They are techniques that access the architecture of experience through experience. Buddhism refers to the most basic elements of conscious experience as *dharma* or phenomena. Such phenomena are described as the ultimate realities or analytically irreducible units of experience. In basic element analysis, these ultimate realities are contrasted to the coherences of everyday life or conventional realities.

The process of breaking conscious reality into its basic elements is similar to Husserl's attempt to discover the fundamental essences of intuition except that it is more successful in two

ways. Firstly, it is rooted in the pragmatic approach of open-ended embodied reflection and so avoids being purely theoretical. It avoids the Idealist tendency to become disconnected from the world. Secondly, unlike cognitivism, by avoiding any ontological claim to the substantive existence of the basic elements basic element analysis avoids any appeal to the Realism that emerges from the reductionism of the analytic rationalists such as Leibniz, Russell and Wittgenstein (Varela, Thompson, and Rosch 1991, pp.117-118). The implications of this position become clear in the following question.

Surely this is an interesting case study – we have here a philosophical system, a reductive system, in which reductive basic elements are postulated as ultimate realities but in which those ultimate realities are not given ontological status in the usual sense. How can that be? Emergents, of course, do not have the status of ontological entities (substances). Might we have a system here in which the basic elements are themselves emergents? The question is all the more interesting because basic element analysis was not simply an abstract, theoretical exercise. It had both a descriptive and a pragmatic motivation (Varela, Thompson, and Rosch 1991, p.118).

In other words, if the basic elements of consciousness have no substantive ontological existence but are nonetheless the most basic units of conscious experience, what kind of entities are they? Given that we know that emergents such as those that form the basis of Minsky and Papert's societies of mind model of cognition also have no substantive ontological status, it is plausible to propose that the basic units of experience are also emergents. On this basis, basic element analysis contributes to the enactive architecture of consciousness and is employed in the forthcoming research analysis.

4.11 The Mental Factors

The mental factors, the relations that bind consciousness to its object, were introduced in section 4.7. Like the aggregates, the mental factors provide a lens through which to consider conscious experience. The first of the omnipresent mental factors, contact, is a process which has two dimensions: cause and effect. As a cause, contact represents the coming together of an object, a sense and the potential for awareness. As an effect, it represents the harmony that arises between these three components. Contact, therefore, does not require any property of sense, object or awareness as cause or as effect, rather, "it is a property of the processes by which they interact, in other words, an emergent property" (Varela, Thompson, and Rosch 1991, p.119). Varela, Thompson and Rosch (1991, p.119) argue that by understanding contact to be both cause and effect, early Buddhism was describing in different terms the logic of self-reference and the notion of circular causality, or feedback and feedforward, that form the basis of the scientific concept of emergence. Contact is an example of emergence applied at a relatively local level whereas, in the concept of codependent origination, emergence is applied at a more global level.

This conceptual equivalence alone lends considerable merit to the scientific enterprise of understanding experience through the logic of emergence. As both cause and effect, contact is also always part of action within the chain of causality.

The second mental factor, feeling, was discussed in section 4.7 as the second aggregate and as one of the links in the chain of causality. Feelings have no independent ontological status and are considered separately from reactions to them. The karma the reactions to feelings perpetuate is considered neutral. Through mindful awareness practice, feelings can be observed and experienced as such. Discernment, the third mental factor, was discussed as the third aggregate in section 4.7. It usually emerges simultaneously with feeling. Through mindfulness, the practitioner can perceive passion, aggression and ignoring (discernment) as no more than emergent impulses which need not necessitate action. These impulses can be transformed into wisdom and compassion.

The fourth mental factor, intention, was discussed in section 4.7 as the means by which volitional actions continue to manifest in later links of the chain of co-arising. By becoming aware of intentions, however, the practitioner can break the links of the chain at craving and recreate intentions. The last mental factor, attention, creates focus for the direction of intention, it holds consciousness to its object. All five of the mental factors, then, are forms of emergent relation.

The five omnipresent mental factors in tandem with alternatively present mental factors combine within consciousness to create the character of any moment of experience (see section 4.7).

The mental factors present at a given moment interact with each other such that the quality of each factor as well as the resultant consciousness is an emergent. Ego-self, then, is the historical pattern among moment-to-moment emergent formations. To make use of a scientific metaphor, we could say that such traces (karma) are one's experiential ontogeny (including but not restricted to learning) ... On an even larger scale, karma also expresses phylogeny, for it conditions experience through the accumulated and collective history of our species. (Varela, Thompson, and Rosch 1991, p.121)

This analysis suggests that, at the level of a single moment, consciousness can be seen as emergent. Similarly, the analysis of causality suggests that the experience of coherence is emergent. Both consciousness and coherence can be explained without an ego-self or any independent ontological entity.

4.12 Operational Closure as an Alternative to Realist Representation

At this point, it is necessary to reassess the concept of representation and the commitment to an external ground that it implies. Varela, Thompson and Rosch (1991) ask:

Why should it be threatening to question the idea that the world has pre-given properties that we represent? Why do we become nervous when we call into question the idea that there is some way that the world is “out there,” independent of our cognition, and that cognition is a re-presentation of that independent world? (Varela, Thompson, and Rosch 1991, p.133)

Cognitivism is explicit in its commitment to representation and the realist conception of the world that follows (Varela, Thompson, and Rosch 1991, pp.134-138). Emergence also employs a realist representation but without the same explicit awareness of this commitment. Realist representation obscures fundamental aspects of observed cognition and for this reason Varela, Thompson and Rosch propose two senses to representation: weak and strong.

In the weak sense representation is simply a means of construal:

This sense is purely semantic: it refers to anything that can be interpreted as being about something. This is the sense of representation as construal, since nothing is about something else without construing it as being some way (Varela, Thompson, and Rosch 1991, p.134).

Representation in this weak sense does not connote any strong ontological or epistemological commitments. This is the sense in which a map represents a particular terrain:

Thus it is perfectly acceptable to speak of a map representing the terrain without worrying about such things as how maps get their meaning. ... Or we can even talk about experiential representations, such as the image I have of my brother, without making any further assumptions about how this image arose in the first place. In other words, this weak sense of representation is pragmatic; we use it all the time without worry. (Varela, Thompson, and Rosch 1991, p.135)

This weak sense of representation provides the possibility of ‘construal’ without the ontological and epistemological commitment to an external world.

The strong sense of representation carries an ontological and epistemological commitment to a pre-given external world. Assuming a world that is given prior to any cognition of it leads to assuming two realms, this pre-given world and cognition of that world. It becomes necessary to hypothesise mental representations of this pre-given world in order to explain the relationship between this world and the apparently separate realm of cognition. These representations become the basis for action. “In the cognitivist version of this story, the map is an innately specified system of representations – sometimes called a “language of thought” – whereas learning to employ this map is the task of ontogeny” (Varela, Thompson, and Rosch 1991, p.136). In the sense that this cognitivist conception of representation focuses our attention on *a posteriori* representations rather than *a priori* representations, it appears to offer an alternative path to the realist or idealist opposition. Nonetheless, this shift to a focus on *a posteriori* representations still assumes a pre-given world, one from which representations are recovered. Consequently, “cognitivism is the strongest statement yet of the representational view of the mind inaugurated by Descartes and Locke” (Varela, Thompson, and Rosch 1991, p.138).

The emergence approach is equally problematic. To illustrate this point, Varela, Thompson and Rosch (1991) contrast more mainstream emergence approaches to the work of Minsky who writes “whenever we speak about a mind, we’re speaking of the processes that carry our brains from state to state ... concerns about minds are really concerns with relationships between states – and this has virtually nothing to do with the natures of the states themselves” (Minsky 1986, p.287 in Varela, Thompson, and Rosch 1991, p.138). In other words, it is not the network of the neurons that create a particular state that is the mind but the relationship between the states themselves. In the emergence approach, these relationships are usually assumed to represent the environment in some way, thus making them mind like. This recommits emergence to a realist representationism because the assumption that such relationships represent the environment leads to the conclusion that the system in question is being *driven by that external environment alone*. Complex systems such as brains, however, are not purely externally driven. They are capable of accepting external input and generating internal input in their own processes. As Minsky points out, “brains use *processes that change themselves* – and this means we cannot separate such processes from the products they produce. ... *The principal activities of brains are making changes in themselves*” (Minsky 1986, p.288 in Varela, Thompson, and Rosch 1991, p.139).

Varela, Thompson and Rosch claim that Minsky’s work signals a shift in the field of cognitive science “away from the idea of the world as independent and extrinsic to the idea of a world as inseparable from the structure of these processes of self-modification.” (Varela, Thompson, and Rosch 1991, p.139). Rather than conceiving of the organism in terms of its responses to external input through *heteronomous* systems, this allows a consideration of the organism in terms of its operational closure. Operational closure is where the results of an organism’s processes are those processes themselves. These self-referential processes “turn back on themselves to form autonomous networks. Such networks do not fall into the class of systems defined by external mechanisms of control (heteronomy) but rather into the class of systems defined by internal mechanisms of self-organisation (autonomy)” (Varela, Thompson, and Rosch 1991, p.140). Such *autonomous* systems do not only invoke the representation of a pregiven world. In fact, they do not necessarily require representation at all.

Instead of *representing* an independent world, they *enact* a world as a domain of distinctions that is inseparable from the structure embodied by the cognitive system. ... In cognitive science, this means that we must call into question the idea that information exists ready-made in the world and that it is extracted by a cognitive system, as the cognitivist notion of an *informavore* vividly implies. (Varela, Thompson, and Rosch 1991, p.140)

In order to operate, self-organising systems do not require the assumption that an independent external ground exists. Meaning is no longer a matter of strong representation. Rather, it could be argued that the failure of strong representation as an explanation for the derivation of meaning shows that meaning is, instead, emergent and potentially intersubjective. The current research uses the weak sense of representation in both the Methodology and the Method. Operational closure is of fundamental importance to the enactive research analysis and discussion and provides a means to reassess the Cartesian anxiety.

4.13 Groundlessness and ‘Common Sense’ as an Alternative to the Cartesian Anxiety

Varela, Thompson and Rosch (1991, p.140) argue that the Cartesian anxiety amounts to a craving after an absolute ground whether this is the outer ground of realism or the inner ground of idealism. Both positions operate from the logic of representation and by treating the inner and the outer as opposites create an endless oscillation between the poles of subjectivity and objectivity and nihilism. The Madhyamika tradition recognises this grasping as the root cause of creating realist and idealist absolutism and nihilism as two extremes (Varela, Thompson, and Rosch 1991, p.143). Mindfulness suggests that the tendency to swing towards nihilism demonstrates a lack of letting go “of the forms of thinking, behaviour, and experience that lead us to desire a ground” (Varela, Thompson, and Rosch 1991, p.141). Grasping after an inner ground in the form of an ego-self is one example. This grasping after an inner ground is a direct parallel to the grasping for an outer ground or object that forms the basis of the realist conception of the world. “We can now begin to appreciate that this grasping after an inner ground is itself a moment in a larger pattern of grasping that includes our clinging to an outer ground in the form of the idea of a pre-given and independent world” (Varela, Thompson, and Rosch 1991, p.143). By ceasing to grasp after an ego-self or an independent world, the two forms of grasping that lead to absolutism, and simultaneously ceasing to grasp at the absence of ground that creates nihilism, it becomes possible to resist the assumption that everything is an illusion. The alternative that arises is to “begin to appreciate that all phenomena are free of any absolute ground and that such “groundlessness” (sunyata) is the very fabric of dependent coorigination” (Varela, Thompson, and Rosch 1991, p.144).

In section 4.7, it was demonstrated that the lack of any permanent ontological entity, such as an ego-self, within the aggregates was a necessary condition for experience. In phenomenological terms, this is to say that “groundlessness is the very condition for the richly textured and interdependent world of human experience” (Varela, Thompson, and Rosch 1991, p.144). This groundlessness emerges in cognition as “common sense” (Varela, Thompson, and Rosch 1991, p.144). Mainstream cognitivism relegates “common sense” and indeed any form of

experience to the domain of “folk psychology” which is viewed as a premature theory that will eventually be replaced by a mature representational theory.

The greatest ability of living cognition, however, consists in being able to pose, within broad constraints, the relevant issues that need to be addressed at each moment. These issues and concerns are not pre-given but are *enacted* from a background of action, where what counts as relevant is contextually determined by our common sense. (Varela, Thompson, and Rosch 1991, p.145)

Common sense represents the self-organising system’s ability to select from the present moment of experience the aspects it needs to pay attention to based on its history. The present moment of experience contains not only sense information and the self-organising system’s own status, as emergence would imply, but also data derived from the self-organising system’s own internal processes, present and historical. In applying common sense, the self-organising system can display a high degree of operational closure merely by principally paying attention to the mental and historical aspects of the present moment. Rather than relegate experience and common sense to folk psychology, Varela, Thompson and Rosch (1991) place them centre stage with their concept of enaction.

4.14 Enaction

Common sense knowledge is not well understood through the framework of propositional knowledge. Rather than being “knowledge *that*”, common sense is better understood as “knowledge *how*” because common sense is formed through the accumulation of past experiences and actions. The objects of the life world that stem from ‘knowledge how’ do not have clearly independent boundaries. Their boundaries are context dependent and depend on the action being performed. Such a life world becomes very difficult, perhaps even impossible, to conceptualise within the strong sense of representation.

Indeed, if we wish to recover common sense, then we must invert the representationist attitude by treating context-dependent know-how not as a residual artefact that can be progressively eliminated by the discovery of more sophisticated rules but as, in fact, the very essence of *creative* cognition. (Varela, Thompson, and Rosch 1991, p.148)

Understanding how an individual enacts meaning by bringing it forth from a background has been the project of philosophical hermeneutics¹⁴ as it was pioneered by Martin Heidegger.

Since Heidegger, continental philosophers have continued to consider the ways in which our experience of being in the world is intimately connected to our bodies, language and social history.

¹⁴ “Hermeneutics, the ‘art of interpretation’, was originally the theory and method of interpreting the Bible and other difficult texts. Wilhelm Dilthey extended it to the interpretation of all human acts and products, including history and the interpretation of human life. Heidegger, in *Being and Time* (1927), gave an ‘interpretation’ of the human being, the being that itself understands and interprets” (Inwood 1998, p.389).

The central insight of this nonobjectivist orientation is the view that knowledge is the result of an ongoing interpretation that emerges from our capacities of understanding. These capacities are rooted in the structures of our biological embodiment but are lived and experienced within a domain of consensual action and cultural history. They enable us to make sense of our world; or in more phenomenological language, they are the structures by which we exist in the manner of “having a world” (Varela, Thompson, and Rosch 1991, p.149-150)

This project has begun to influence cognitive science. The principal challenge that this continental non-objectivist philosophical tradition presents to cognitive science is the need to relinquish the assumption that the world can be independent of the knower. Cognitive science, on the other hand, challenges continental philosophy with the task of linking the study of culturally embodied experience with the observations of cognitive science. Varela, Thompson and Rosch (1991) come to two crucial conclusions:

If we are forced to admit that cognition cannot be properly understood without common sense, and that common sense is none other than our bodily and social history, then the inevitable conclusion is that knower and known, mind and world, stand in relation to each other through mutual specification or dependent coorigination. If this critique is valid, then scientific progress in understanding cognition will not be forthcoming unless we start from a different basis from the idea of a pre-given world that exists “out there” and is internally recovered in a representation. (Varela, Thompson, and Rosch 1991, p.150)

What does it mean to say that the mind and the world “stand in relation to each other through mutual specification or dependent co-origination” (Varela, Thompson, and Rosch 1991, p.150)? Varela states in *Steps to a Science of Inter-being* that: “the mind is not in the head” (Varela 1999a, p.72). Mind arises from the completely embodied process of actively coping with the world. It is the organism’s active handling of the objects of the world that forms the basis of the subject. Equally, the arising of the objects of the world is dependent on the subject actively engaging with them. In other words, you “cannot see the object as independently being ‘out-there’”. The object arises because of your activity, so, in fact, you and the object are co-emerging, co-arising” (Varela 1999a, p.73).

To emphasise the importance of the active aspect of mind, Varela discusses the well known experiment involving two kittens. The first explores the world whilst pulling the other in a cart behind it. The first kitten acted normally when released from its load. The kitten that had been restrained, however, was unable to navigate space. The experiment shows how the very concept of space arises from an active engagement in movement.

Cognition is something that you bring forth by the act of handling, by the fact of doing it actively. It is the very foundational principle of what mind is all about. That entails, as I tried to show above, that it is a deep co-implication, a co-determination of what seems to be outside and what seems to be inside. In other words, the world out there and what I do to find myself in that world, cannot be separated. The process itself makes them completely

interdependent, quite literally so, as seen with the example of the kittens. (Varela 1999a, p.73)

Mind arises not in some imaginary inner space, nor purely as a reaction to an outer reality, but in the “non-place of the co-determination of inner and outer” (Varela 1999a, p.73). Mind is also a product of the entire organism. Varela, Thompson and Rosch (1991, p.173) bring these elements to fruition in the concept of embodied action or enaction. The term “embodied” here acknowledges that experiences arise within the context of having a body with sensorimotor capacities and these sensorimotor capacities are “embedded in a more encompassing biological, psychological and cultural context” (Varela, Thompson, and Rosch 1991, p.173). The term “action” emphasises the fact that the actions of these sensory motor processes are fundamental to cognition. In effect, cognition is action.

In a nutshell, the enactive approach consists of two points: (1) perception consists in perceptually guided action and (2) cognitive structures emerge from the recurrent sensorimotor patterns that enable action to be perceptually guided. (Varela, Thompson, and Rosch 1991, p.173)

Varela, Thompson and Rosch (1991, p.176) discuss numerous examples of perceptually guided action. They show how Jean Piaget’s “genetic epistemology” can be considered demonstrative of how cognitive structures emerge from recurrent patterns of sensorimotor activity. Their discussion of colour perception is particularly informative¹⁵.

According to the enactive approach, cognition is the enactment of the world based on a history of viable structural coupling. Viable (rather than optimal) couplings retain the ontogenal¹⁶ and phylogenal¹⁷ integrity of the system. This viability requires only a proscriptive, rather than prescriptive logic. “Thus cognition as embodied action both poses the problems and specifies those paths that must be tread or laid down for their solution” (Varela, Thompson, and Rosch 1991, p.205). This model provides an understanding of the “aboutness or intentionality of cognition as embodied action” (Varela, Thompson, and Rosch 1991, p.205). Intentionality is expressed through the directedness of action. Intentionality is what the system assumes the possibilities for action to be given how the system understands the world to be. In terms of how the world satisfies, or fails to satisfy, the system’s understanding of these possibilities for action, intentionality becomes how the resulting actions fulfil, or fail to fulfil, the assumed possibilities. Enaction understands a cognitive system either by describing the structure of the system and its subsystems or by describing the behaviour of the system in terms of the forms of coupling it is capable of. In employing these two perspectives, cognitive scientists can understand how a

¹⁵ See chapter 8 of *The Embodied Mind* (Varela, Thompson, and Rosch 1991, pp.147-184) for further detail.

¹⁶ Ontogeny refers to the “origin and development of the individual being” (1989).

¹⁷ Phylogeny refers to “the genesis and evolution of the phylum, tribe, or species; ancestral or racial evolution” (1989) or history.

particular environment constrains a cognitive system and how this cognitive system represents these constraints.

In so doing, we are able to explain how regularities – sensorimotor and environmental – emerge from structural coupling. The research task in cognitive science is to make transparent the mechanisms by which such coupling actually unfolds and thereby how specific regularities arise. (Varela, Thompson, and Rosch 1991, p.206)

In the enactive approach, the environment tends to recede into the background in comparison to cognitivism or emergence” (Varela, Thompson, and Rosch 1991, p.207). The environment “now enters in explanations only on those occasions where systems undergo breakdowns or suffer events that cannot be satisfied by their structures” (Varela, Thompson, and Rosch 1991, p.207). This leads to a shift in our concept of intelligence. Rather than being the capacity to solve problems, it becomes the capacity to “enter into a shared world of significance” (Varela, Thompson, and Rosch 1991, p.207).

4.15 The Enactive Ontologically Fragile Self

The self that steps forward from the background of enaction is one that Varela describes as virtual or ontologically fragile. Such a self is in constant motion, continually inventing and reinventing itself (Varela in Scharmer 2000, pp.4-5). The ontologically fragile self is not made real through identification with some permanent substance. Instead, the self is made real through its ability to tackle both the endogenous and exogenous aspects of the world and continually renew itself in this process. Crucial to this process of creation and recreation is the gesture of letting go (Varela 1999a , p.73).

This is the nature of virtuality. What this is saying to me is if you really want to get closer to understanding what it means to be a subject, you’d better understand that this is the constant generator of what that subject is all about – since it is not a stable, solid entity, since it is not within the head, since it is not just in language. It’s in none of those dimensions, it’s somehow in a figure of multiple levels of emergence, but it is always fragile. ... So virtuality is not just this absence of a central self; it also has that kind of **fragile flotation** of coming and going, which is where the letting go is. Letting go is an interesting gesture, because in fact it’s almost like invoking the virtuality of the self, just putting it spontaneously on the table. Usually it’s life that makes you let go. You know what I mean, in the extreme cases of sickness or danger, or the disappointment of love, it just forces you into that gesture of letting it be, letting it go. It’s interesting that human beings do have the capacity to mobilize that capacity all the time. ... A life of wisdom is to be constantly engaged in that letting go, and letting the virtuality or the fragility of the self manifest itself. When you are with someone who really has that capacity to a full-blown level, it affects you. When we meet those kinds of people, it’s clear, because the whole process is not individual, it’s not private, and you enter into that kind of resonance. (Varela in Scharmer 2000 pp.10-11)

Through letting go, this ontologically fragile self is continually engaged in a transformational process of becoming more real: more virtual. Varela comments: “you know, the paradox of being more real means to be much more virtual, and therefore less substantial and less

determined. But that's more real; that seems to correspond more to what it is" (Varela in Scharmer 2000, pp.11-12).

Returning to the discussion of emergence, Varela (1999a, p.75) refers to the interactions amongst local elements of a system as 'local rules'. These local interactions are dynamic, fast and often simultaneous. Global processes, such as the self, emerge from these local rules. Such global states cannot be reduced to their local rules but neither are they independent of them. Varela (1999a, p.75) claims that the resultant cognitive unities have a different ontological status to local rules.

I behave as a coherent unity, not a mere juxtaposition of movement, voice, sight, and posture. I'm an integrated, more or less harmonic unity that I call 'myself' or 'my' mind, and you interact with me at that level: 'Hi, Francisco.' That interaction is happening at the level of individuality, which is the global, the emergent. Yet we know that the global is at the same time cause and consequence of the local actions that are going on in my body all the time (Varela 1999a, p.75).

This entity 'Francisco' does not have any material existence. It cannot be localised or identified with any substance. Nonetheless entities such as 'Francisco' do exist. Such emergent entities, Varela (1999a, p.76) claims, are typical of the complex entities that are found throughout the realms of life. They are enactively emergent, highly effective modes of action and presence within the world. "It's a co-determination of neural elements and a global cognitive subject. The global cognitive subject belongs to that emergent level and it has that mode of existence" (Varela 1999a, p.76).

The global cognitive subject experiences itself at the global level, the 'user' level, and despite its different ontological status the self is still able to influence local elements.

It's a two-way street: the local components give rise to this emergent mind, but, vice versa, the emergent mind constrains, affects directly these local components. ... So from this point of view, the puzzle of psychosomatic phenomena is a false problem. Why should we be surprised that a global state of a cognitive mood or an attitude or a state of mind could have a direct effect on very, very minute local principles? (Varela 1996, pp.76-77)

This is what Varela describes as a "*distinct region of ontological reciprocity*" between the material body (*Körper*) and lived experience (*Leib*) (Thompson 2007, forthcoming, p.83). Although Western disciplines such as cognitivism have long accepted that the mind is supported by matter, they have resisted the corollary, that matter can be affected by the mind. Varela (1999a), like Gendlin (2002), claims this omission is demonstrably incorrect.

Failing to recognise this two-way street obscures an important implication of operational closure: that the "mind is fundamentally a matter of *imagination and fantasy*" (Varela 1999a, p.77). The mind is continuously engaged with the internal activity of its own emergent properties as well as its coupling with the world. Although the body perceives locally, the mind both

emerges from the local-global transitions that create emergent properties and constantly organises these emergent properties into an apparently coherent reality. “Stated in other words, perception is as imaginary, as imagination is perception-based” (Varela 1999a, p.77). None of the mind’s emergent properties such as memory, affect or vision are discrete. Affect or emotion, for instance, has been found to be fundamental to our ability to cope with the world and contributes to our ability to reason.

Reason is what occurs at the very last stage of the moment-to-moment emergence of mind. Mind is fundamentally something that arises out of the affective tonality, which is embedded in the body. It takes about a fraction of a second for the whole thing to happen, over and over and over again. In the process of a momentary arising of a mental state, the early stages are rooted in the sensory motor surfaces near the spinal cord in the mid-brain, then they sweep upward on to the so-called limbic system, into the so-called superior cortex, so this emotional tone changes transforming into categories and distinct elements and chains of reasoning, which are the classical unities description of mind. But reason and categories are literally the tips of the mountain which are sitting on affect, particularly affect and e-motion. In fact, e-motion is already intrinsically cognitive. Once you change your perspective and stop looking for reason as the most central principle of mind, then you can see the emergence of a moment of mind as it happens. It starts out from this soup, the entire organism in situation, and then it gives rise to this surge, which gradually spreads out like peaks of mountains. ... That is why experience in a phenomenological footnote is so hard to articulate, since a large chunk of its base is pre-reflective, affective, non-conceptual, pre-noetic. It’s hard to put it into words, precisely because it precedes words. To say it precedes words does not mean it’s beyond words. It’s the opposite, it’s because it’s so grounded that it has not yet become the elements of reason that we tend to think are the highest expressions of mind (Varela 1996, p.78).

From this perspective, psychosomatic phenomena are no more of a problem than the mind/body dualism: they are a normal part of the organism’s functioning. Proprioception and emotion as embodied emergents are some of the most obvious examples of functioning at the mind/body ‘interface’. They are examples of how matter affects mind and vice versa.

The enactive mind arises not from internal processes alone, nor as a simple reaction to an external world but rather in the ‘non-place of the co-determination of inner and outer’. The actions of an enactive mind are determined as much by internal input and the need to enact meaning by bringing it forth from a background of accumulated experience, including our social and bodily history, as by the immediate sense experience of the world.

5. Theoretical Background to the Methodology

5.1 Introduction

The interview method employed in this research is first-person psycho-phenomenological (Vermersch 1999; Vermersch 2009; Petitmengin 2009; Petitmengin and Bitbol 2009). The broader intention, however, is that the phenomenological findings of the research be used to elucidate existing neurological research and, likewise, that these neurological studies inform the phenomenological findings. Such an exchange could preface strictly neurophenomenological research.

The second enactive approach, presented by Torrance (2005), directly aligns with a strict definition of neurophenomenology as the intersection of neurology, cognitive science and phenomenology. Neurophenomenology was originally defined as follows:

Neuro-phenomenology is the name I am using here to designate a quest to marry modern cognitive science and a *disciplined approach* to human experience, thus placing myself in the lineage of the continental tradition of phenomenology. [footnote: The use of ‘neuro’ should be taken here as a *nom de guerre*. It is chosen in explicit contrast to the current usage of ‘neurophilosophy’, which identifies philosophy with anglo-american philosophy of mind. Further, ‘neuro’ refers here to the entire array of scientific correlates which are relevant in cognitive science. But to speak of neuro-psycho-evolutionary-phenomenology would be unduly cumbersome.] (Varela 1996 p.330)

The footnote above provides an important disclaimer on the ‘neuro’ in the definition of this field. Varela appears to intend neuro-phenomenology to mean interdisciplinary scientific phenomenology in the interests of cognitive science and not merely the intersection of neurology, cognitive science and phenomenology.

Research on psychosomatic disorders, I would argue, would benefit from the application of cognitive science in tandem with an interdisciplinary scientific phenomenology. Such research needs to bring to bear the ‘entire array of scientific correlates which are relevant in cognitive science’ to the psychosomatic and in a manner that is open to circulation with the phenomenological.

As Torrance comments, the middle way between Idealism and Realism proposed by enaction is a means by which the science of cognition can be used as a basis to a science of consciousness (Torrance 2005). Research into psychosomatic phenomena stands to benefit substantially from a science of consciousness that enlists an interdisciplinary scientific phenomenology.

Perhaps there is a way to draw on Varela’s definition of neurophenomenology to inspire a science of cognition and a science of consciousness that are complemented by an interdisciplinary scientific phenomenology for the consideration of psycho-somatic phenomena.

Such sciences stand to have broad application. Given practical considerations it may not be possible to combine all the necessary aspects of these sciences within a single study. It will, therefore, be necessary to consider how individual studies can be designed to coordinate with other studies to fulfil all the necessary requirements.

As background to these suggestions, and the theoretical application of the core of neurophenomenology, the mutual constraints between the mental and the material, in the research discussion, the necessary aspects of neurophenomenology are discussed in section 5.2. The discussion of neurophenomenology presented here is necessary to section 6.9 where the connections between Gendlin, Greimas and first-person psycho-phenomenological explanations of experience are developed. Section 5.2 builds on the previous sections 4.5 to 4.15.

The remainder of this chapter introduces theoretical concepts that are required by a first-person phenomenological method. Working definitions of phenomenality, phenomenal data and experience are provided in section 5.3. These definitions support sections 6.5 to 6.10 in the next chapter. Arguments for the irreducibility of first-person phenomenal data are presented in section 5.4. This section relies on the discussion of mindful awareness presented earlier in section 4.5. In section 5.4, the relevance of phenomenal data for the subject and the way in which this first-person perspective captures the subjects' perspective on their experience are discussed. The implications of this first-personal relevance for the definition of objectivity from both first and third-person perspectives and the circulation between these positions are also discussed in section 5.4.

The necessary tenets to any first-person methodology are presented in section 5.5. The core process of becoming aware, *epoche*, is introduced, including its three components: suspension, redirection and letting go. *Epoche* is described in more detail in section 6.3 and is fundamental to the interview technique used in this research and described in section 7.6. The role of intuitive evidence and 'know how' for the process of becoming aware is examined in section 5.5. The plasticity of experience is recognised and the developmental processes that are necessary to the cultivation of competence for the first-person subject are acknowledged. Competence and its relation to validity in first person research is further discussed in sections 6.10 and 7.6.10.

The second-person as an empathic resonator is introduced in section 5.6. The role of the second-person within phenomenal research as a means to facilitate the expression and validation of phenomenal data is presented. Fundamental to any phenomenal methodology that employs the second-person are the key concepts of intersubjectivity and empathy. The philosophical roots of the concept of intersubjectivity are discussed in section 5.7. Intersubjectivity engages the 'problem of other minds'. The present position of cognitive science with respect to the 'problem

of other minds’ and the ways in which this position can be informed by phenomenology are discussed in section 5.7. Through the Husserlian concepts of ipseity¹⁸ (I-ness) and self-alterity (otherness) ‘thou’, ‘we’, ‘other’, ‘world’ and ‘I’ are presented as relative rather than oppositional. Similarly, in section 5.7, the relation between the mind and the lived body is shown to contribute to an understanding of intersubjectivity as open and embodied. The generative and intentional aspects of consciousness are outlined and affect is presented as an exemplary intersubjective event. A conceptual framework for the intentional and generative aspects of changes in consciousness is critical for the present research. Toward this requirement, the contributions of section 5.7 are extended by the discussion of Gendlin’s theory of the generation and symbolisation of meaning from experience presented in sections 6.2 and 6.7.

A discussion of the role of empathy within neurophenomenological research is presented in section 5.8. Broadly, empathy is defined as an intentional intersubjective process that acknowledges the other as an expressive intentional being. Empathy is a self-displacing and self-othering act. The four states of empathy operative within first-person research are presented and the implications for objectivity and subjectivity of including empathy within a methodology are discussed.

Empathy and intersubjectivity are fundamental premises to first-person phenomenological research and intersect in Thompson’s (2007, forthcoming) concept of enculturation. Enculturation is outlined briefly in section 5.9 and revisited in section 12.7. Empathy, intersubjectivity and enculturation are also important to the discussion of the validity of phenomenal data presented in sections 6.10 and 7.6.10, epoche and elicitation as developed in section 5.5 and 6.3, and to the interview technique discussed in section 7.6.

5.2 Neurophenomenology and the Pragmatics of Reciprocal Constraints

Methodologically neurophenomenology bridges the ‘explanatory gap’ (see Appendix L), promotes cooperation between qualitative and quantitative approaches, and addresses the philosophical issues a science of consciousness poses to present understandings of subjectivity and objectivity in a manner that provides an appropriate platform for the present enquiry. Founded by Francisco Varela, neurophenomenology does not seek to reduce the phenomenological to the natural (Varela 1996; Varela 1997, 1999b).

We seek to produce epistemological and ontological shifts whereby the two domains of natural objects and phenomenological descriptions can provide a three-dimensional view of mind and experience altogether. From this perspective, any dualist extreme, whether reductionist/objectivist, or transcendentalist/mentalist is a declaration of failure. Moving beyond these antinomies is precisely what is at stake here if we are to avoid yet another

¹⁸ Ipseity refers to “personal identity and individuality; selfhood” (1989).

repetition of the compulsive history of pendulum swings between favoring nature or a *Geistiges* domain. (Varela 1997, p.360)

Varela makes clear what this implies with respect to the science of consciousness.

Very specifically, the kind of naturalization we seek could not be found in “merely” finding the neurobiological (brain or body) correlates of consciousness, since this would leave in the shadow the precise *circulation* between them. In other words, what needs to be addressed is the fact that human experience encompasses properties of *both* the material and the mental without contradiction. The question is thus not so much how to naturalize Husserlian phenomenology, but rather what should a natural science (such as the cognitive sciences) become to be fully adequate to phenomenological descriptions that could be naturalized but not epistemically reduced. (Varela 1997, p.360)

Although neurophenomenology is informed by neurology its name does not imply that the material aspect of neurophenomenological research is limited to a consideration of neurology alone. The neurophenomenological methodology avoids reducing mind to body or vice versa, whilst placing centre stage their necessary relation. In my view, this provides the ideal platform for the research of psychosomatic disorders such as CFS. Psychosomatic disorders are so called precisely because their ‘human experience encompasses properties of both the material and the mental’. The fundamental question neurophenomenology asks is: how can this naturalisation be achieved? What form can the circulation between the mental and the material take?

Varela (1997) argues that it is in the region of the lived body that access to both phenomenological data and the natural elements of cognitive science can be found. The lived body is the locus where the close relationship between *Lieb* and *Körper*, experience and its grounding, takes place. Varela claims that “once the constitution of natural objects is adequately thematised in the phenomenological realm, pure experiences can also be considered as belonging to a psychological consciousness and hence belonging to an organism. In this precise sense data rooted in *lived first-hand experiences are intrinsically open to a non-reductive naturalization*” (Varela 1997, p.369). Consequently, neurophenomenology considers issues of embodiment central and proposes a circulation of mutual or reciprocal constraints between the natural and the phenomenological: “phenomenological accounts of the structure of experience and their counterparts in cognitive science relate to each other through *reciprocal constraints*” (Varela 1997, p.369).

The nature of the sought for circulation is none other than one of mutual *constraints* between both accounts, including both the potential bridges and contradictions between them. The unresolved middle ground and the circulation between the terms are, by necessity, where the various views and approaches to mutual circulation will separate themselves out. (Varela 1997, p.370)

Through the use of mutual constraints, neurophenomenology and the enactive approach to cognitive science enable an understanding of the material and mental aspects of experience that

do not stand in contradiction but, instead, mutually inform each other. In application to the experience of CFS, rather than treat these two realms of experience as distinct this approach allows for research that is more comprehensive and research that attends to the condition on terms that are in closer alignment with the experience of CFS.

Mutual constraints are not to be conflated with a correlative approach or an analytic isomorphism which suggests that there is a locus in the brain where neural activity is isomorphic to phenomenality (Varela 1997, pp.370-71). Varela considers phenomenal isomorphism, in which neural causal mechanisms must be isomorphic to phenomenal data, more adequate than analytic isomorphism but questions whether it is possible to separate phenomenal description and natural explanation in the manner assumed by these approaches. Instead, neurophenomenology requires that reciprocal constraints be mutually generative passages.

A more demanding approach will require that the isomorphic idea is taken one step forward to provide the passage where the mutual constraints not only share logical and epistemic accountability, but they are further required to be operationally *generative*, that is, where there is a mutual circulation and illumination between these domains proper to be in a position to generate in a principled manner reduction analysis and eidetic descriptions that are rooted in an explicit manner to biological emergence. (Varela 1997, p.372)

It is in the *Körperlieb* that such a mutual reciprocity without explanatory residue exists.

Varela puts forward three levels of mutual constraint that provide a generative triple-braid to link the natural and the phenomenal:

- I) the formal level since eidetic descriptive structures and implementation partake of the same mode of ideality and hence are effectively on common ground;
- II) the natural bodily process at the right level spanning across two levels of global emergence and local mechanisms that assure a direct relevance to both the psychological content if examined phenomenologically and to a detailed scientific examination;
- III) the pragmatic level of the *Lieb/Körper*¹⁹ transition since it, and it alone, can have a situated bi-valence, that excludes neither and provides the relevant basis or data for the preceding threads. (Varela 1997, p.380)

Lutz presents these threads as follows:

- 1. phenomenological data and invariant structural features of experience (thread #1)
- 2. neural and somatic substrates (thread #2)
- 3. formal dynamical models (thread #3) (Lutz 2002a p.149)

Varela (1997, p.381) proposes that these three factors, functioning as the core of neurophenomenology, will provide the foundation for a non-dual philosophy and a science of consciousness. Unlike dualism the neurophenomenological triple braid approach to the ‘explanatory gap’ does not require extra ontological entities. This pragmatic approach instead

¹⁹ *Lieb*, *Körper* and *Körperlieb* are used here in Husserl’s sense. *Lieb* means living or lived. *Körper* means body or bodily. *Körperlieb* refers to ‘the lived body’. For further explanation of these terms as Varela uses them, see Varela (1997) p.369, particularly footnote 19.

aims to attend to the multi-perspectival circulation between the natural and the phenomenological (Lutz 2002a).

With respect to formal descriptive structures, Varela proposes a parallel between phenomenology and mathematics. The nature of this link, he suggests, will be clarified in the process of neurophenomenological research but his principal claim here is that the invariants of experience can be discovered and that this will allow a formalisation of the phenomenal (Varela 1997, p.373). ‘Phenomenal invariants’ refer to the “categorical features of experience that are phenomenologically describable both across and within the various forms of lived experience” (Lutz and Thompson 2003, p.32). In his original formulation of invariants, Husserl drew inspiration from the calculus of variations to form the perceptual, individual and imaginative universal aspects of the concept of invariants (Depraz 1999b, pp. 101-102). Varela frames these differently.

Francisco distinguished three scales of lived time: the 1 scale, of about one second, which corresponds to the time of a conscious moment and to which “nowness” belongs; the 1/10 scale corresponding to minimal separable perceptual events; and the 10 scale corresponding to narrative time. (Rudrauf et al. 2003, p.52)

In the research interviews I am principally concerned with events on the 1 and 10 scale, the now and the narrative time scales.

Importantly, neurophenomenology does not require the invariants of experience to be fixed. Rather, the creativity of consciousness causes invariants to continually emerge.

With respect to the relationship between local and global emergence, Varela claims that neurophenomenology can draw on the language and mechanisms of non-linear dynamical systems. These dynamical tools are creating radical re-configurations within the domains of ontology and reshaping classical mechanical views of causality and explanation (Varela 1997, p.374-5).

The key point I wish to retain here is that these major scientific developments break from the traditional opposition between matter and life, and provide substance to a modern biology where such dialectical contraries are simply no longer relevant. Similarly, in the cognitive sciences, the traditional opposition between body and mind, or between the biological organic base and the mental and cognitive properties is also simply erased as a fundamental gap. In both cases the erasure of the traditional ontological barriers is done in a non-reductive manner since the new theoretical moves actually *retain* the specific properties of both traditional regions. (Varela 1997, p.375)

In this way, theoretically and methodologically, neurophenomenology makes use of an embodied large-scale dynamic approach to the neurophysiology and neurodynamics of consciousness (Lutz and Thompson 2003, p.31).

On the pragmatic level, by considering invariant experience to be emergent, neurophenomenology stresses the need not to treat the phenomenological domain as a fixed corpus of knowledge but, rather, one that is open to systematic investigation and continuous refinement.

The adoption of a properly phenomenological attitude is an important methodological prerequisite for exploring original constitutive structures and categories of experience, such as egocentric space, temporality and the subject/object duality, or spontaneous affective and associative features of the temporal flow of experience rooted in the lived body. (Lutz and Thompson 2003, p.38)

This requires the systematic production and reproduction of phenomenological descriptions. Methods for the study of the phenomenological need to be precise and precisely distinguished from the methods of experimental cognitive psychology and the attitude of philosophical phenomenology (Varela 1997, p.376). Such a pragmatic requires the development of a new skill and opens up a new realm of data. It needs to be systematically theorised and cultivated in training over time (Varela 1997, p.377).

This means not only (i) that the subject is actively involved in generating and describing specific phenomenal invariants of experience, and (ii) that the neuroscientist is guided by these first-person data in the analysis and interpretation of physiological data, but also (iii) that the (phenomenologically enriched) neuroscientific analyses provoke revisions and refinements of the phenomenological accounts, as well as facilitate the subject's becoming aware of previously inaccessible or phenomenally unavailable aspects of his or her mental life. (Lutz and Thompson 2003, p.33)

In this manner, gathering first-person subjective data from trained subjects becomes an heuristic²⁰ strategy and constraint on the process of identifying and theorising the physiological processes relevant to consciousness. The result of this circulation equally informs the conscious experience of the subject (Lutz and Thompson 2003, p.32).

For examples of neurophenomenological research and a discussion of how the present research is positioned in relation to those studies, see Appendix K.

5.3 Experience, Phenomenality and Phenomenal Data

The first-person method employed in this research enlists the notion of phenomenal data as the means by which the phenomenality of experience can be studied (Lutz and Thompson 2003, p.3). Varela and Shear (2003) follow Nagel's definition of phenomenality as that which refers to the 'what it is like to be' of lived experience. Lived experience refers to "experiences as they are lived and verbally articulated in the first-person, whether it be lived experiences of perception,

²⁰ Heuristic in the sense of "serving to find out or discover" (1989).

action, memory, mental imagery, emotion, attention, empathy, self-consciousness, contemplative states, dreaming, and so forth” (Lutz and Thompson 2003, p.32).

Clearly ‘what it is like to be’ a bat or a human being refers to how things (everything) look when being a bat or a human being. ... It is what something is for something else; it is the *being for* by opposition to a being in itself independently of its apprehension by another entity. (Roy et al. 1999, p.3)

The participants’ verbal expression of their experience of CFS provides this research with the phenomenal data through which the phenomenality of CFS is examined. Third-person accounts are about the apprehension of an entity by another. In contrast, it is the perceived relation, the ‘being for’ rather than the ‘being in itself’, or, the ‘what something is to’ one’s experience of that entity that provides the content of phenomenal data. First-person accounts give us access to ‘what something is for something else’ in as far as we are consciously aware of this relation. This does not preclude the notion that there can be non-conscious experiences of relation for which data may be gathered. How it is to be a bat or a human being will only be evident to the bat or the human being to a certain extent. Nor is this distinction between conscious and non-conscious phenomena to be taken as fixed. Using appropriate methods of observation phenomena that are usually only perceived pre-reflectively can be brought into conscious awareness. This highlights the importance of using methods that are appropriate to the level of phenomena being examined (Roy et al. 1999, p.4). Phenomenal data are not synonymous with qualia²¹ (Roy et al. 1999, p.9-10).

5.4 First-person Irreducibility, Objectivity and Circulation with the Third-person

The first-person position is defined as “the lived *experience* associated with cognitive and mental events” (Varela and Shear 1999a). This phenomenological consciousness or conscious experience exists in the sense that it is the aspect of consciousness that is “relevant and manifest *for* a ‘self’ or ‘subject’ [who] can provide an account” of that conscious experience (Zahavi 1999, p.1). It is this relevance to the subject, in particular, that makes the first-person position different to third-person descriptions of phenomena.

The contents of third-person descriptions are not as specifically tied to the agents that create them. This is not to deny the human element to science, rather, it is to acknowledge that such descriptions “refer to properties of world events without a direct manifestation in the experiential-mental sphere” (Varela 1996, p.1).

²¹ “The terms ‘quale’ and ‘qualia’ (plural) are most commonly understood to mean the qualitative, phenomenal or ‘felt’ properties of our mental states, such as the throbbing pain of my current headache, or the peculiar blue afterimage I am experiencing now” (Levin 1998, p.863).

Such 'objective' descriptions do have a subjective-social dimension, but this dimension is hidden within the social practices of science. The ostensive, direct reference is to the 'objective', the 'outside', the content of current science that we have today concerning various natural phenomena, such as physics and biology. (Varela and Shear 1999a)

The objective status of knowledge generated from the third-person position comes to be considered 'objective' because it is generated through specific scientific methods endorsed by the scientific community as the appropriate means for the constitution of a body of shared, regulated knowledge. The constitution and regulation of such knowledge is validated and verified through human exchange. Objective knowledge is therefore only partly constrained by the empirical, natural phenomena it claims to study. Knowledge generated from the third-person position is always inherently partly subjective (inside) and partly objective (outside).

This brief reminder that the subjective is already implicit in the objective highlights how the received distinction between objective and subjective as an absolute demarcation between inside and outside needs to be closely scrutinized. *Mutatis mutandis*, dealing with subjective phenomena is not the same as dealing with purely *private* experiences, as is often assumed. The subjective is intrinsically open to intersubjective validation, if only we avail ourselves of a method and procedure for doing so. (Varela and Shear 1999a)

The purely objective status of third-person accounts cannot be taken for granted. This reassessment of the relationship between the objective and subjective, first and third-person provides the possibility to further develop the first-person position and methods for its scientific study.

First-person accounts involve an irreducible givenness (Varela and Shear 1999a). They are "not an explanatory posit, but an explanandum in its own right" (Varela 1996, p.209). "Lived experience is where we start from and where all must link back to, like a guiding thread" (Varela 1996, p.334). Zahavi provides a review of Anscombe, Castaneda and Shoemaker's arguments for the irreducibility and nonsubstitutability of the first-person (Zahavi 1999). By implication, first-person accounts cannot be reductively eliminated. Instead, they must be understood through a form of non-reductive explanation. This does not imply that such accounts are purely private experiences. In his conversation with Varela, Scharmer asserts: "without the experience of the other, you could never perceive your self" (Scharmer 2000, p.8). Varela concurs:

The first reaction people have is that [the first person is] just a personal thing. That it's private. But the notion that the first person is private is a disaster. The first-person access is as public as the third person, okay? When you have a third-person point of view, clearly you need a first person who does the measurements and does the writing, etc., but [provides] a social network to which it is going to be addressed. So the key point is that it's really not very meaningful to speak about consciousness or experiences being private. **There is a quality to experience where you need a mode of access that you might want to call the first-person access. That doesn't make it private. It's just as social as everything else.** (Scharmer 2000, p.8)

First-person accounts do not involve any privileged form of access to experience. Their irreducibility does not provide them with any final epistemic status. Such accounts are open to systematic evaluation. What is the significance then of the claim that the first-person position is a ‘given’ which cannot be reduced to that which is available from the third-person position?

For science to study experience it must be accepted that the subject has a perspective on experience. For the experiencer the first-person position exists. It is an inescapable aspect of experience and to ignore it would imply “amputating life of its most intimate domains, or else denying science explanatory access to it” (Lutz and Thompson 2003, p.4). This aspect of experience appears to the experiencer at the ‘level of the user’. When I move my hand from the first-person position, my experience of this action is not principally about a combination of muscle tones which can be observed from the third-person position. Rather, I experience this action as a complex of motor intentions. These intentions operate on an emergent level that I can report but that is not available to the third-person observer. As such the study of this ‘user level’ of consciousness requires a unique methodology.

What is privileged about the first-person position is the unique access point it provides in relation to processes of change and learning. The present research is particularly interested in the phenomenal changes that occur in the movements through illness to recovery. This research is concerned to acknowledge the participants’ first-person perspective on these experiences. Varela and Shear argue that disciplines which have traditionally used the first-person position to bring about change demonstrate some of the most effective methods for studying first-person accounts of experience and some of the most compelling evidence that this can be done. “In all these domains there is abundant evidence not only that the realm of experience is essential for human activity and life involving the use of one’s own mind, but that the experiential domain can be explored, as we see in transformations mediated by specific practices and human interactions in prescribed settings (training courses, sports coaching, psychotherapeutic sessions)” (Depraz, Varela, and Vermersch 2003, p.4).

Just as third-person knowledge claims evolve and establish their objectivity through the systematic application of justified methods which have been endorsed by the scientific community, so, too, first-person examinations of experience must be generated using appropriately developed methods.

The apparent familiarity we have with subjective life must give way in favour of the careful examination of what it is that we can and cannot have access to, and how this distinction is not rigid but variable. It is here that methodology appears as crucial: without a sustained examination we actually do not produce phenomenal descriptions that are rich and subtly interconnected enough in comparison to third-person accounts. The main question is: How

do you actually *do* it? Is there evidence that it *can* be done? If so, with what *results*? (Lutz and Thompson 2003, p.2)

In response to these questions Varela and Shear (2003) turn their attention to the common features of the disciplines that have worked with first-person accounts of experience. They trace the commonalities within these disciplines and draw together an outline of the necessary aspects to any method that studies experience.

5.5 A Methodology for the First-Person Study of Experience

First-person methods involve a disciplined practice that increases the subjects' sensitivity to their experiences. This entails a systematic training of attention and the self-regulation of emotion. "This capacity enables tacit, pre-verbal and pre-reflective aspects of subjective experience—which otherwise would remain simply 'lived through'—to become subjectively accessible and describable, and thus available for intersubjective and objective (biobehavioural) characterization" (Lutz and Thompson 2003, p.37). Varela and Shear present two main dimensions which they consider necessary to the systematic study of conscious experience.

- (1) Providing a clear *procedure* for accessing some phenomenal domain.
- (2) Providing a clear means for an *expression and validation* within a community of observers who have familiarity with procedures as in (1). (Depraz, Varela, and Vermersch 2003, p.6)

The distinction between the act of experiencing by following a procedure and providing validation through regulated intersubjective exchange is not absolute (Depraz, Varela, and Vermersch 2003, p.7). This section focuses on the 'basic attitude' or 'epoche', as an example of a clear procedure for accessing phenomenality. According to Depraz, Varela, and Vermersch (2003, p.25), "The use of the term 'epoche' in neurophenomenology is derived from the Greek term *epokhè* and is influenced by Husserl's appropriation of the Greek term". Epoche consists of three basic gestures: suspension of the 'natural attitude' that appearances are truly the state of the world, redirection of attention inwards, and letting go or accepting what comes (Depraz, Varela, and Vermersch 2003, p.25). Expression and validation are explored in section 5.6.

To illustrate the above dimensions Varela and Shear (2000) discuss three existing first-person methods: introspection, phenomenology and meditation. For introspection, the act of paying attention to a defined task is the procedure, and validation is provided through mediated verbal account. For phenomenology, the act of reduction-suspension is the procedure and identifying descriptive invariants makes validation of accounts possible. For meditation, the suspension of mental activity and the use of sustained attention and awareness are the procedures and the participants' accounts and scientific studies of meditation act as forms of validation.

Each of these existing methods has a different emphasis. Varela and Shear (2003) consider that, of the three, meditation has the most highly developed procedures but tends to rely heavily on ‘inside’ accounts for verification whereas phenomenology and introspection are stronger with respect to verification (Depraz 1999b, p.7).

The procedural phase, within which an individual experiences something, Varela and Shear (1999b) label L1, the lived content of the experience. Next, the participant is required to examine or become aware of the content of L1. This experience of examining one’s own mentation is labelled L2. L2 will contain the content of L1 and content related to the manner in which the examination of L1 was achieved or accessed (Depraz 1999b, p.98). In order to become aware, to achieve L2, the participant must redirect their mentation; they must turn their thought back upon itself. This ‘conversion’ or ‘redirection’ requires an apperceptive act which moves attention away from the ‘exterior’ content of the world towards the ‘interior’ mental act of perception itself (Depraz, Varela, and Vermersch 2000, p.123-5). This requires the suspension or interruption of normal mentation (which does not stop to examine itself). Varela and Shear call the ability to suspend and redirect mental processes, to move from L1 to L2, the ‘basic attitude’ as opposed to the ‘natural attitude’ (Gallagher and Varela 2003). Suspension of the ‘natural attitude’ does not imply that the ‘natural attitude’ is denied or that the contents of the ‘natural attitude’ are automatically brought into doubt (Thompson 2007, forthcoming, p.24-25). Rather, suspension allows a redirection that focuses on the everyday things precisely as they are experienced and perceived. As such, redirection is a “procedure of working back from the ‘what’ to the ‘how’ of experience” (Thompson 2007, forthcoming, p.25). This redirection of mentation may be mediated by another but this is not always necessary (Lutz and Thompson 2003, p.8). The ability to pursue this ‘basic attitude’ to a richer level, however, is often where the role of the second-person is required. Varela and Shear call this ‘phenomenal filling-in’. First-person methods may specify an appropriate means through which the participant can explicitly ‘express’ the content of their experience in a way that is open to ‘intersubjective validation’ (Lutz and Thompson 2003, p.11). This verbalisation or expression “of phenomenal invariants provides the crucial step whereby this sort of first-person knowledge can be intersubjectively shared and calibrated, and related to objective data” (Lutz and Thompson 2003, p.38).

Employing phenomenological terms, this process of “becoming reflectively attentive to experience” is referred to as ‘epoche’ (Lutz and Thompson 2003, p.37). “The ‘epoche’ mobilizes and intensifies the tacit self-awareness of experience by inducing an explicit attitude of attentive self-awareness” (Lutz and Thompson 2003, p.37). This meta-awareness pays attention to “the manner in which something appears” and “implies flexibility of attention, in particular being

able voluntarily to shift one's attention and stabilize or sustain it on a given mode of presentation" (Thompson 2007, forthcoming, p.26).

Depraz considers three conceptions of the act of phenomenological reduction or epoche: the Cartesian way, the psychological way and the way of the life-world (Depraz 1999b, pp.102-106). Depraz argues that both the Cartesian and psychological forms of reduction are solipsist²² and, consequently, in their approach to intersubjectivity they are inadequate to the study of experience. The Cartesian and psychological forms of reduction reinforce the fallacy of the privacy of the first-person perspective. In contrast, the way of the life-world, true to its Husserlian heritage, is a perceptual act performed by an embodied subject located within the life-world. Similarly both Gendlin (1999) and Ginsburg (1999) take the body as their focal point in the development of first-person methods.

The corporeality of epoche of the life-world points towards affect as an open form of active perceptual attention and acts as the basis of intersubjectivity. It becomes immediately clear that the first-person is not purely private.

Only the way which passes by way of the life-world takes account of the communitarian dimension of the reductive experience. I am not the only one to apprehend myself at every instant as an operative subject and, in addition, others, co-actors in this experience, may equally work to develop this experience more correctly and more intensely in me. ... the reductive path of the life-world proceeds towards an immersion in an embodied sensibility in which we all share as incarnate subjects. ... The result is decisive. Sense and affect, far from being – as Descartes naïvely thought – enemies which lead us astray and deceive us, are rather to be regarded as our 'allies' that can help us. They are the privileged support of the transformation, of the alteration (*Veränderung*) of ourselves in which, in the end, the reductive experience consists. (Depraz 1999b, p.105)

This intersubjective, embodied, living act of reduction provides a continual renewal of a dual sense of self, simultaneously theoretical and existential. What is at stake, Depraz (1999b, p.97) argues, is the 'phenomenological scientificity' of the praxis of reduction, a praxis which needs to be simultaneously practical and theoretical. This requires of the theoretical that it not render invisible the practical. From an enactive perspective, this same need not to divorce the theoretical from the pragmatic, was discussed in sections 4.4 and 4.5.

Suspension and redirection are two components of the core process of becoming aware, or epoche, of moving from L1 to L2. In his conversation with Scharmer, Varela outlines a third component: letting go. Initially, when one suspends one's habitual stream of thought, nothing happens. If one tolerates this 'nothing happening' for long enough "suspension will lead to very early emerging events, contents, patterns, gestures, whatever" (Scharmer 2000, p.5). It is then possible, within the space that the gesture of suspension has created, to perform the gesture of

²² Solipsism is "the view or theory that self is the only object of real knowledge or the only thing really existent" (1989).

redirecting one's attention to the new, the emerging events, contents and gestures that arose from the act of suspension. In order to return to the state of suspension from redirection, however, it is necessary to make the gesture of letting go.

Unlike our habitual paying attention, exploring experience requires what we call here letting go. It has to be a light touch. If you redirect to the phenomenon of examining experience in a heavy-handed way, you get what you ask for. In other words, you're embarked in your associations and thoughts, and again, you're overcome by your habitual mindstream. But the letting go here is crucial, because it's only when you don't hold on to the redirection that you can again go back to suspension. And this process, this core process, goes through and through. It doesn't necessarily go anywhere, you just keep doing it. (Scharmer 2000, p.5)

Letting go is also referred to as 'receptivity' (Depraz, Varela, and Vermersch 2000). This 'receptivity' is necessary to broaden the field of attention, it is a reception "to a *letting-come*, about which there is nothing passive other than the name. In fact, it eminently involves action" (Depraz, Varela, and Vermersch 2000, p.129).

In varying degrees, the reflectable is not immediately available. It doesn't exist other than as a potential and will not come as revelation other than through a cognitive act borne by a particular intention. And so the gesture of letting-go presupposes a waiting, but is focused and open and so eventually void of content for a time, without any immediate discrimination other than "there is nothing", "it's foggy", "it's blurred", "it's confused", "nothing's happening". (Depraz, Varela, and Vermersch 2000, p.130)

What accompanies the three components of epoche, what steps into this void, is an intuitive evidence which has its own internal obviousness: "In other words, epoche and intuitive evidence call to each other, so to speak" (Depraz, Varela, and Vermersch 2000, p.123). Intuition lies between the suspension of epoche and expression and validation and requires epoche as the condition under which it may emerge with a 'lightning bolt' temporality (Depraz, Varela, and Vermersch 2003, p.53). Intuition cannot be actively induced, rather it requires a waiting for and an acceptance.

Depraz, Varela, and Vermersch (2003) trace the history of the concepts of intuition through the work of Descartes, Kant and a number of later German idealists (Depraz, Varela, and Vermersch 2003, pp.44-46). These authors outline a tension between the concepts of intuition that describe intuition as an elementary, singular, individual experience and an intersubjective intuition that is universal and provides a unique form of access to knowledge (Depraz, Varela, and Vermersch 2003, p.44). These authors draw upon Husserl's understanding of intuition as an intersubjectively available grounding principle of knowledge. For Husserl, intuition refers to that which is directly given in plenitude (*Fülle*) and fulfillment. Principally, intuition is either given through perception (*Gegenwärtigung*) or imagination/memory (*Vergegenwärtigung*) (Depraz, Varela, and Vermersch 2003, p.45).

The objects of intuition often show up as novel and surprising. In this sense the intuitive appears to be discontinuous, it emerges in a manner that ruptures the normal train of experience. Intuition is creative: “What is at stake here is the *creativity* of thought, which we have to sharply distinguish from the “mediate” activity which presents itself as a reflexive activity and whose every step follows the preceding one according to the laws governing the coherence of contents in our experience” (Depraz, Varela, and Vermersch 2003, p.48). Depraz, Varela, and Vermersch (2003) propose ‘three ensembles of criteria’ by which intuition from the first-person perspective may be recognised: the cognitive, emotional and properly intersubjective points of view.

1. First, from *the cognitive point of view*: on the one hand, confusion, incompleteness, absence, whiteout, emptiness, nothingness, unreadiness, that which still moves within, and on the other hand, clarity, distinctness, evidence, completion, stability, coherence, being finished, “at peace”.
2. Next, from *the emotional point of view*: the feeling of adequation, of justice, or aesthetic success, of joy, of a profound satisfaction, of global congruence when the criterion is fully satisfied, or of surprise and frustration or disappointment if it is not.
3. Finally, from *the properly intersubjective point of view*, participating at the same time in the cognitive (the constitution of objectivity) and the affective (conviction by means of empathy): the experience of an inner conflict or the force of assent, of being carried along by a convincing argument which makes you approve of it as soon as you agree to recognize its truth. (Depraz, Varela, and Vermersch 2003, p.63)

This understanding of intuition, although eidetic, is not apodictic in the Husserlian sense although it endeavours to preserve “Husserl’s demand for intuitive evidence as an ‘infinite horizon of approximations tending towards the idea’, that is, a process of growth wherein different forms of evidence participate in establishing new knowledge in a corpus proper to a community” (Depraz, Varela, and Vermersch 2003, p.62).

Suspension, redirection and letting go, as the components of epoche and accompanied by intuitive evidence, are the principal aspects of the first-person study of experience. These provide a clear procedure for accessing the phenomenal domain. In this research suspension, redirection and letting go provide the initial components of a ‘model’ for the actions that are necessary for the participants to undertake in the process of expressing their experience of CFS. What these discriminations imply for all first-person methods is the need to make a distinction between experiential content and the process(es) involved in ‘coming up with’ that content. Different methods place a different emphasis on each of these. Introspection and phenomenology place more emphasis on content and thus require the participant to be able to move from L1 to L2 with ease. Meditation, on the other hand, places more emphasis on identifying the processes through which content arises with the goal of ceasing these processes and thus achieving a state of pure consciousness by eradicating content completely (Scharmer 2000, p.8). For the purposes of gathering phenomenal data, regardless of what method is considered, it is the ability to suspend

mentation and reflect on this mentation, to move from L1 to L2 that provides phenomenal accounts with their richness. Without this ability, such accounts remain flat and poor (Scharmer 2000, p.8).

Although cognitive science has taken the use of first-person accounts in the laboratory for granted since the beginning of the twentieth century, Varela argues that this is only a spontaneous beginning.

Spontaneous capacity, which is already part of science, needs to be developed further. Something that is spontaneous and natural is the beginning of the whole process of learning, where you become truly a black belt or a very competent observer of your experience, a describer of your experience. By means of what? One key thing: disciplined regular training. Without specific regular training, like everything else in human affairs, you stay a beginner. ... We are pushing beyond just verbal reports to all forms of other techniques of explorations and expressions, which requires a whole new methodology. (Scharmer 2000, p.2)

Varela stresses the need to patiently cultivate the ability to observe and describe one's own experience. Cultivation is required to "sensitize individuals to their own mental lives through the systematic training of attention, emotion regulation, and metacognitive awareness" (Thompson forthcoming, p.3). Without such cultivation the use of the first-person within cognitive science will remain problematic for numerous reasons (Lutz and Thompson 2003, p.32). Each of the gestures of suspension, redirection and letting go need to be cultivated. Just as a beginner must practice in order to learn to play a musical instrument, participants in phenomenal studies will need practice at phenomenal methods. Discovering how to suspend and examine mentation requires sustained discipline and learning and this process has its own developmental time frame for each practitioner (Lutz and Thompson 2003, p.8).

Phenomenological training modifies experience; it demonstrates that experience is dynamic and 'plastic'. These procedures "help to stabilize phenomenal aspects of this plasticity so that they can be translated into descriptive first-person reports" which allow for rigorous intersubjective corroboration (Lutz and Thompson 2003, p.39). Studies of the specific experiential affective state of loving-kindness or compassion strongly suggest that, with practice, plasticity can be stabilised and experiential states can be induced (Lutz et al. 2004). The physiological correlates of such approaches are under investigation and they are being used in clinical and health programmes (Lutz and Thompson 2003, p.37). Such studies have shown, for instance, that the cultivation and use of mindfulness can be used in the treatment of chronic pain, anxiety disorders, fibromyalgia, epilepsy, psoriasis, hypertension, depression, HIV-positive men, breast, prostate and other forms of cancer (Carlson et al. 2003). Cultivating and inducing

mindfulness²³ has been shown to consistently enhance immune function, reduce negative affect, increase positive affect, reduce perceived stress and enhance perceived quality of life (Carlson et al. 2003; Davidson et al. 2003; Kabat-Zinn, Lipworth, and Burney 1985).

Developmental processes imply change. Consequently an allowance must be made for changes within participants in studies of conscious experience. This extension of participant capacity is a significant part of what Varela is referring to when he asserts the need for science to develop new methods and methodologies for the study of conscious experience. Concomitant to these processes of change is the need to distinguish different levels of competence.

It's like karate science. You've got to distinguish between the kid who just came for the weekend and the eminent master... In experiments you need to distinguish the strategies that different people have to do, and determine the level of competence that people need. (Scharmer 2000, p.2).

What these different levels of competence represent is the participants' 'know-how'. "It is the know-how that counts, not the know-what. When you get to this point, the know-what is only used to get started, but it is the know-how that counts and that is going to be transformative" (Scharmer 2000, p.9). Just as common sense experience involves 'know-how' it is through learning and practising that the experiencers²⁴ of each of an individual's senses develop the 'know-how' required to become competent at assessing and transforming their experience.

A method based on these principles may attract what Varela and Shear (1996) label the 'excavation fallacy' or 'hermeneutical objection'.

How do you know that by exploring experience with a method you are not, in fact, deforming or even creating what you experience? Experience being what it is, what is the possible meaning of examination? (Varela and Shear 1999b, p.13)

To this objection Varela and Shear (1996) reply that first-person data does not need to be free from the influences created by its method of observation in order to be valid: "every examination is an interpretation, and all interpretation reveals and hides away at the same time" (Varela 1996, p.14). Likewise such a method will not be entirely free of the entities that it examines. This lack of methodological neutrality does not imply that any disciplined examination of experience creates nothing but artefacts or distorted versions of experience.

²³ "The practice of recognizing emptiness in every moment is known as the practice of mindfulness/awareness or samatha-vispasnya. Essentially a radical not-doing, it is traditionally understood as a universal practice, but despite having been refined and explored for 2500 years by over half the world, it was never discovered independently in the West. Instead of a space for the human in the analyst's studio required in psychoanalysis, samatha-vispasnya creates the space through non-action, which includes nonresponse to language" (Varela 1992, p.66).

²⁴ "Despite the atmosphere of debate that surrounded some issues, there was unanimous agreement on the more experientially direct claim that each of the senses (eye, ear, nose, tongue, body, and mind) had a different consciousness (recall Jackendoff) – that is, at each moment of experience there was a different experiencer as well as a different object of experience." (Varela, Thompson, and Rosch 1991, p.69)

To be sure, the exploration of experience will suffer along with all other methodological investigations from cultural expectations and instrumental bias, but there is no evidence that the phenomenal data gathered are not equally constrained by the proper reality of conscious contents. (Varela 1996, p.14)

This problem is not unique to first-person methods, however the study of experience does involve an important difference. This objection hinges on the assumption that what is being observed has some static, neutral or natural state that must be captured in order to appreciate it accurately. Experience is not one dimensional in this manner.

This is fine if we reject the assumption (as I do) that there is some kind of well-defined standard for what should count as real or normal experience: experience appears to be inherently open-ended and pliable, and hence there is no contradiction in saying that sustained training in a method can make available aspects of experience that were not available before. (Varela 1996, p.346)

It makes no sense to talk of experience as if it was pure or raw. It is always fluid and changing and the act of exploring it is already, to whatever end, a part of human activity. The realm that first-person methods allow us to explore is the realm of “potentially valid intersubjective items of knowledge, quasi-objects of a mental sort. No more, no less” (Varela and Shear 1999b, p.14). First-person methods will not be method-free but this does not preclude the possibility of mindfully employing such methods to constructive ends. It is a question of finding a middle ground (Varela and Shear 1999b, p.14). There is growing evidence that first-person experience can be explored, examined and transformed systematically (Varela and Shear 1999b).

Varela emphasises that third and first-person accounts are most powerful when they are mutually informing.

It is quite easy to see how scientific accounts illuminate mental experience, but the reciprocal direction, from experience towards science, is what is typically ignored. ... The study of experience is not a convenient stop on our way to a real explanation, but an active participant in its own right. (Varela 1996, pp.343-44)

To this end Varela and Shear (2003) argue that third and first-person accounts need to be harmonised and mutually constraining and to do so first-person accounts must be appropriately linked to objective empirical research. What this allows in the present research is the ability to move from first to third person seamlessly. This opens two possibilities: the possibility of investigating first-person accounts of the experience of CFS and extrapolating from these potential third-person investigations and the possibility of relating this first-person data to the third-person evidence available in the existing experimental literature on CFS. In establishing such a relationship of “reciprocal influence and determination”, Varela and Shear propose the second-person position (Scharmer 2000, p.2).

5.6 The Second-Person Position

Varela and Shear (2000) observe that existing methods that examine experience often initially require a mediator or second-person. This second-person is often already adept at the task under examination. Although not directly familiar with the participants' lived experience (L1), the mediator assumes the position of having 'been there' to some extent and, using this empathy as their basis, coaches the subjects' learning process. The second-person locates the first-person as the expert. Both then engage in a process of making the implicit explicit. Varela claims that, like the first-person, the second-person already exists within cognitive science but only in a mode that is much closer to the third-person position than is required by a science of consciousness.

This partner can have two modes. One is a mode which is slightly closer to the third-person position. That is verbal reports. It is what many cognitive scientists do. They place themselves in the position of admitting that you have the mind, that you can have access from the first person to what I just showed you. So they admit the position of first person, but at the same time they remain a little bit removed. They are content with taking notes and noticing whatever it is that you say. In contrast, **a more interesting second person is really empathetic**. He (sic) admits that you have in your mind an access to your experience, but this person himself knows the kind of experience you're talking about and therefore acts as a coach. **The good sports coach cannot be somebody who hasn't done the sport. The coach must have first-person access to his own experience that perfectly resonates with yours. For example, in Buddhism, you have to advance and progress in this cycle with a qualified teacher.** A qualified teacher is who? A second person. Because he can then make the process work through mutual resonance and correct it. (Scharmer 2000, p.7)

Extending phenomenal methodologies that enlist the first-person requires the construction of methodologies that allow for the second-person position and for such second-persons to fully develop into empathic resonators. This conception of first, second and third-person highlights the fact that each position is "structured not so much in regards to what content they address, but in the *manner in which* they appear – inserted in the network of social exchanges" (Depraz, Varela, and Vermersch 2003, p.9). The necessary distinction is not between the public and the private or the purely objective and subjective but rather the way in which these positions function within the social practices of knowledge construction. How these positions intersect and relate is crucial to the ability of the researcher to harmonise first and third persons and promote their mutual constraint. The three positions are not concretely given categories, rather they reflect the requirements of the complex social networks they are situated within (Depraz, Varela, and Vermersch 2003, p.82).

The third-person position forms the basis of all forms of scientific reductionism; it emphasises the subjective/objective, internal/external dichotomy in an effort to create a pure objectivity that eliminates the researcher from view. Cognitive science and the science of consciousness challenge this position by taking, as the external data, the internal workings of the

subject whilst also recognising that the subject is implicated in the study of themselves. In contrast to the third-person position, the second-person position takes the external behaviours of another as traces or manifestations of their internal mental life. Like Dennett's heterophenomenologist (Depraz, Varela, and Vermersch 2003) the second-person creates from these behaviours a model of the internal life of another. Akin to the anthropologist, who tries to become a member of the tribe, the second-person retains a certain critical distance but otherwise acts like an empathic resonator.

In fact, that is how he sees his role: as an empathic resonator with experiences that are familiar to him and which find in himself a resonant chord. This empathic position is still partly heterophenomenological, since a modicum of critical distance and of critical evaluation is necessary, but the intention is entirely other: to meet on the same ground, as members of the same kind. ... The position here is not that of a neutral anthropologist; it is rather one of a coach or a midwife. His/her trade is grounded on a sensitivity to the subtle indices of his interlocutor's phrasing, bodily language and expressiveness, seeking for indices (more or less explicit) which are inroads into the common experiential ground, as we shall elaborate below. Such encounters would not be possible without the mediator being steeped in the domain of experiences under examination, as nothing can replace that first-hand knowledge. (Depraz, Varela, and Vermersch 2003, p.10)

The second-person position makes possible "*exchange between situated individuals* focusing on a specific experiential content developed from the first-person position" (Depraz, Varela, and Vermersch 2003, p.81). The empathic resonance of the second-person is not uncritical but it attempts to construct a common ground that is based on a familiarity with the kind of experience being explored (Depraz, Varela, and Vermersch 2003, p.84). For the purposes of this research, the second-person position provides a clear role for the researcher.

The second-person position provides a means for 'expression' and 'validation'. These two phases of becoming aware are optional to the basic cycle of epoche (Depraz, Varela, and Vermersch 2003, p.65). 'Expression' refers to all the means of signification. 'Expression' that uses language is referred to as 'verbalisation'. The act of 'verbalisation' does not necessarily occur simultaneously with the act of reflecting on the experience that is verbalised. The simultaneous verbalisation that is assumed possible by disciplines such as psychology overlooks the fact that reflecting on lived experience can "soak up most of our mental capacity" (Depraz, Varela, and Vermersch 2003, p.67). Such an approach does not allow for the 'letting come' or 'letting arrive' of epoche and the temporality of intuitive evidence. In support of this view Depraz, Varela, and Vermersch (2003) observe that when a subject is reflecting on an experience they are most often silent. Any form of expression, such as 'verbalisation', involves a process, a particular act of suspension and a specific quality of intuitive evidence (Depraz, Varela, and Vermersch 2003, pp.68-70). Depraz, Varela et al. detail these aspects of expression drawing a distinction between "*expression of the product* of the reflecting act and *the expression of the*

reflecting act itself” (Depraz, Varela, and Vermersch 2003, p.65). The authors discuss both autonomous verbalisation and the role of second-person mediation in this process and the use of both written and oral reporting (Depraz, Varela, and Vermersch 2003, pp. 73-74).

Although ‘expression’ and ‘validation’ are mutually implicative, validation most often requires a linguistic act (Depraz, Varela, and Vermersch 2003, p.65). “Validation intrinsically concerns the intersubjective establishment of criteria of veracity in an investigation” (Depraz, Varela, and Vermersch 2003, p.80). It is only through a research community putting in place the means to intersubjectively validate descriptive categories that experience can be elaborated. The mode of validation within a research project is, therefore, very dependent on the relations between first, second and third-person in any given context and, conversely, those relations are equally dependant on the chosen modes of validation (Depraz, Varela, and Vermersch 2003, p.82). This said, fully accomplished intuitive insight can be considered the most immediate first-person form of validation (Depraz and Cosmelli 2003, p.170). Depraz, Varela, and Vermersch (2003) propose four stages to the process of ‘validation by practice’.

1. The existence and determination of the *reference experience* [*vécu de référence*] (E1), that is, what is grasped as a target by the reflecting act.
2. The *qualities of the act* by which this lived experience (E1) is reflected upon; this act of reflection is thus another lived experience (E2).
3. The *qualities of the verbal description* of E1 (truth, completion, fine-grained quality).
4. The *analysis of results* that have issued from the descriptive verbalization. (Depraz, Varela, and Vermersch 2003, p.86)

Depraz, Varela, and Vermersch (2003) provide a detailed account of the interactions between these aspects of validation and their relation to the basic cycle of epoche and intuitive evidence (Depraz, Varela, and Vermersch 2003, pp.86-96). The authors discuss how the intersubjective contradiction that arises from ‘inter-individual variability’ can be a source of richness that deepens both the description of phenomenal invariants and their validation (Depraz, Varela, and Vermersch 2003, p.94). This conception of expression through verbalisation provides the research with the further components to the ‘model’ of the actions that are necessary for the participants to undertake so that validation of the phenomenal domain may become possible.

In circumstances where a separate mediator is not necessary the subject may take up the position of the second-person themselves. In such cases the subject would look towards their actions or expressions for validation of their model of their own mentation.

This call for intersubjective validation is not obligatory in every case. But the converse is: there is no possibility of first-person methodology in our sense of the term without at some point assuming the position of direct experience that seeks validation. Otherwise the process then becomes purely private or even solipsistic. (Depraz, Varela, and Vermersch 2003, p.11)

Depraz, Varela et al. show that forms of validation range from those that are intrinsically internal and closest to the first-person position to those that are primarily forms of third-person validation (Depraz, Varela, and Vermersch 2003, pp.78-96). Meditative traditions, for instance, provide validity criteria that focus on a “careful verification of the presence and properties of the results arrived at along the way of [the meditator’s] own paths of experience” (Depraz, Varela, and Vermersch 2003, p. 78). These traditions are focused more towards the internal first-person end of the spectrum whereas phenomenology puts “forth the strong, and extremely strict, criterion of apodicticity and the intuitive criterion of lived experience” (Depraz, Varela, and Vermersch 2003, p.79).

It is entirely possible that a subject might engage in constructing an imaginary world that would be regarded by others as an illusion. What is critical here is that for a method to examine the first-person it must involve some form of second-person mediation. Varela and Shear argue that this mediation role is unique to first-person methods. Such empathic resonance requires “a sustained dedication and interactive framing before significant phenomenal data can be made accessible and validatable” (Frith 2002, p.11).

The process whereby experience can be translated into verifiable report is, according to Frith (2002), one of the major programmes for science in this century. First, second and third-person positions form a dynamic continuum of validity strategies which are constitutively open to each other (Depraz and Cosmelli 2003, pp. 166-168). Within each position there are variations and within any process of validation a combination of positions may be used in complement (Depraz and Cosmelli 2003, p.165). This is particularly the case for the second-person position which is more “a plastic spectrum of interaction” or “a relational dynamics in which we are unavoidably immersed” than an “isolated entity” (Depraz and Cosmelli 2003, p.165). Depraz and Cosmelli provide an assessment of these multifarious positions (Depraz and Cosmelli 2003, pp. 175-182).

With this circulation between first, second and third-person position, first-person research brings into focus two key issues: intersubjectivity and empathy.

5.7 Intersubjectivity

In Western philosophy, the concept of intersubjectivity is generally associated with the ‘problem of other minds’ and the classical argument from analogy (Thompson and Zahavi 2007, forthcoming, p.33). Both the theory-theory and the simulation-theory in social cognition and cognitive science share common assumptions with the argument from analogy. These arguments treat mental life as distinct from outward behaviour by assuming that intersubjectivity involves representing “unobservable, inner mental states on the basis of outward behaviour” (Thompson

and Zahavi 2007, forthcoming, p.34). First-person phenomenology (Depraz 2001) contests the common assumption that underpins this view: that the mind is in the brain and that brains, being spatially discrete, are totally separate from each other.

Again, it does not cease to amaze me how some philosophers of mind have spent litres of ink on debates about how to prove that you have a consciousness and that we are not surrounded by zombies. Quite frankly I find this ludicrous. This issue is squarely upside down: the presence and reality of other is so intimately close that the pertinent question is how can we ever come to have the notion that we are that separate and distinct? (Depraz 2001, p.79)

These assumptions wrongly juxtapose individuality and intersubjectivity. Instead, Varela argues that intersubjectivity and individuality are necessarily complementary.

The phenomenological tradition provides rich and sometimes competing accounts of intersubjectivity (Depraz 2001; Kern and Marbach 2001; Zahavi 2001). A convergence between these accounts and Eastern practices and conceptualisations of intersubjectivity is emerging (Arisaka 2001; Depraz 2001; Wallace 2001). Zahavi calls for a systematic synthesis of phenomenological accounts of intersubjectivity and reviews the features that they share (Zahavi 2001, pp.165-166). Broadly, the phenomenological tradition questions whether the mind is solitary and exclusively internal. “The problem with this assumption is that our initial self-acquaintance is not with a purely internal, mental self, for we are embodied and experience our own exteriority, including our bodily presence to the other” (Thompson and Zahavi 2007, forthcoming, p.35). Phenomenology also questions whether the only direct access we have to the other is through our external perception of their physical movements. “The problem with this assumption is that what we directly perceive is intentional or meaningful behaviour – expression, gesture, and action – not mere physical movement that gets interpreted as intentional action as a result of inference” (Thompson and Zahavi 2007, forthcoming, p.35). These critiques prompt a reassessment of the assumption that mind is an essentially inner mental state in contrast to the purely outer behaviour of body.

Phenomenologists such as Merleau-Ponty emphasise that expression is more than a bridge between the inner and outer, it is a “direct manifestation of the subjective life of the mind” (Thompson and Zahavi 2007, forthcoming, p.35). Subjective life is communicated to the subject through the ‘lived body’ of the other. Through empathy, a unique form of intentionality, I am directed towards the lived experience of the ‘other’ as an “intentional being whose bodily gestures and actions are expressive of his or her experiences or states of mind (Thompson and Zahavi 2007, forthcoming, p.36). These interactions are capable of changing the constitution of the lived body (Savage-Rumbaugh, Fields, and Tagliabue 2001, p.290).

Drawing on Husserl, Zahavi's (1999) discussion of the self-awareness that is associated with the first-personal given experience of the *cogito* places particular emphasis on the constitutive role for the subject of alterity (otherness).

For both Husserl and Sartre, mundane self-awareness entails a self-apprehension from the perspective of the Other, and it therefore has the encounter with the Other and the Other's intervention as its condition of possibility. It is, in other words, a type of self-awareness which does not have its origin in the self but depends upon *radical alterity*. When I experience the Other as experiencing myself and when I take over the Other's objectifying and alienating apprehension of myself, my self-awareness is mediated by the Other. (Zahavi 1999, p.164)

It is through the experience of the 'other' that the self experiences itself as a self within a world of others and as an object amongst objects. Without 'thou', 'we', 'other' and 'world' there is no 'I': the concepts 'I' and 'other' are relative. The ontological implications of this conception of intersubjectivity are that 'self', 'other' and 'world' are inseparably interconnected and reciprocally illuminating (Zahavi 2001). The self encompasses an openness to the 'other': an intersubjectivity (Zahavi 1999, pp.164-166). Thompson refers to this as open intersubjectivity (Thompson 2001, p.15). Evidence for this concept of intersubjectivity is emerging from affective neuroscience, cognitive ethology, evolutionary neurobiology, developmental neuroscience, developmental psychology, and the philosophy of mind and psychology (Cheyne 2001; Thompson 2001, pp.5-13). The recent discovery of mirror neurons in cognitive neuroscience is further evidence for intersubjectivity (Gallese 2001).

For Husserl, self-alterity involves self-alteration, the 'inner opening' within egoic subjectivity through which the self is continually self-altering and self-altered. Self-alterity is by definition non-unified and self-alteration, a dynamic process. In this way, consciousness is generative and intersubjectively open (Depraz and Cosmelli 2003, pp.180-81).

Consciousness, for Husserl, is intentional, which does not mean first and foremost deliberate or wilful, but rather simply a *directedness* towards the external object and an *openness* to the world. In that respect, intentionality can be active or passive, voluntary or driven, attentional or affective, cognitive or emotional, static or genetic. Furthermore, open-directedness indicates a strong relativization of the subject/object polarity. (Depraz and Cosmelli 2003, pp.179-180)

Phenomenology identifies the directedness and openness of experience as a dynamic structure referred to as transcendence. "Phenomenologists understand transcendence as a dynamic structure of experience – experience aims beyond itself and is always already open to what is other" (Thompson 2005 p.272). This allows for experiential change and creativity.

Furthermore, Husserl argues that it is the experience of the interplay between the ipseity and alterity of one's bodily awareness that underpins the ability to recognise the 'other' as an intentional embodied being. "Consequently, prior to any concrete perceptual encounter with

another subject, intersubjectivity is already present as co-subjectivity in the very structure of perception” (Gallagher and Varela 2003, pp.105-6; Thompson and Zahavi 2007, forthcoming, p.37). In this way, objectivity is intersubjectivity constituted.

My experience of the world as objective is mediated by my experience of and interaction with other world-engaged subjects. Only insofar as I experience that others experience the same objects as myself, do I really experience these objects as objective and real. (Thompson and Zahavi 2007, forthcoming, p.38)

It is through “intersubjective regulation” that the subject or researcher validates experience such that it can be shared (Depraz and Cosmelli 2003, p.163). This requires a “re-styled objectivity founded on such ruled inter-individual practices” (Depraz and Cosmelli 2003, p.163). This embodied intersubjectivity extends beyond the membrane of the organism into its environment “especially the interpersonal, social world of self and other” (Thompson 2001, p.2). Varela uses his own experience of receiving a liver transplant to demonstrate tangibly these elements of intersubjectivity.

This inescapable intersubjectivity (the ‘team’) of mental life shapes us through childhood and social life, and in the transplantation experience takes a tangible form as well. But it is also true in the organism’s very embodiment, appearing as the depth of space, of the intrinsically extensible nature of its sentience, especially in exploring the lived body. (Varela 2001, p.262)

An evaluation of the similarities between phenomenology and Buddhism with respect to ipseity and alterity is provided by Thompson (2005 p.272).

Historically, objectivity has been described as both necessary and universal. This stems from philosophy’s emphasis on identity and permanence. “Movement and mobility therefore never could acquire the dignity of scientific objects: the deadlock of the Heraclitean flux as well as Zeno’s paradoxes attest to this clearly” (Depraz and Cosmelli 2003, p.188). An intersubjective objectivity of consciousness in alignment with quantum physics and dynamical systems theory takes instability as constitutive, no longer “a side-effect of a phenomenon initially defined by its stability” (Depraz and Cosmelli 2003, p.188). This implies that “variability (which involves singularity) needs to be considered as a genuine component of scientific objectivity” (Depraz and Cosmelli 2003, p.189).

An intersubjective methodology which takes this concept of objectivity as its basis needs to employ several main components: a subject that is open to all aspects of a given phenomena, including its situated individuated multidimensionality, the production of a full categorising description and an awareness of the need for the experimenter to adopt the same attitude of openness (Depraz and Cosmelli 2003, pp.191-2). Depraz and Cosmelli discuss the heuristic

processes by which categories emerge, stressing that these often coincide with the moment of account (Depraz and Cosmelli 2003, p.192).

Depraz and Cosmelli discuss the validity of retrospective categorisation by reference to the phenomenality of categorisation in the moment of the experience. They treat retrospective categories as necessarily dependent on and arising from the phenomenality of the original experience:

... it is important to become attentive to the way our descriptive categories emerge to our mind as the experience unfolds and develops ... [the categorising process] results as a gradual back-and-forth between certain categories and the unfolding of the experience. Hence the necessary *heuristic* character of such gradually and experientially produced categories ... before we are able to meet any validating categories, that is objectifying (universal and necessary) ones. (Depraz and Cosmelli 2003, p.193)

They propose three types of categories: “(1) expressive categories, which are both bodily, either strictly organic (sensory-kinesthetic) or behavioural (gestures and actions); (2) literary-linguistic categories, which belong to the *significant* dimension in Saussure’s terminology, be they onomatopoeic words, images, and metaphors or again periphrases; (3) technical linguistic categories, which are culturally inherited in a broad sense, either as dialectical notions or educationally transmitted as a specific *Bildung* (domain of formation)” (Depraz and Cosmelli 2003, p.193).

Depraz and Cosmelli propose three criteria for validating variability which enhance the objective validity of the given phenomena:

- (1) individual training as a means to develop more stability in the self-observation and self-description of one’s own experience
- (2) intra-individual trials distributed along a specific temporal period in the life of the individual subject, which enable one to compare different performances of the same individual and better evaluate their more-or-less successful results
- (3) inter-individual sharing of a given experience, which allows the emergence of conflicting descriptions but also of convergent analysis. (Depraz and Cosmelli 2003, p.194)

The authors discuss a number of case studies where these criteria are applied.

Affect is a prime example of an intersubjective, ‘two-organism’, self-other event. Embedded in bodily-awareness and action, affect involves most of the somatic systems in the body, the “pleasure-displeasure valence axis; social signalling and coupling; and conscious evaluation and assessment” (Thompson 2001, p.4). Affect is intersubjectively perceived through the embodied comportment of the other, rather than through any simulation of an emotional state. This affective comportment plays a substantial role in the individual’s understanding of the mental state of the other even when the other is not a human being (Gallagher and Varela 2003; Savage-Rumbaugh, Fields, and Taglialatela 2001; Smuts 2001; Thompson 2001). “It is here that

we see affective comportment blossoming into empathy, in the sense of a meta-affective cognitive capacity for grasping another's point of view" (Thompson 2001, p.5).

Varela describes all cognitive phenomena as emotional-affective. He claims that mind is generated from affective-empathic phenomena. This is demonstrated by research that shows that what distinguishes children and higher primates from other animals is not their capacity for language but, rather, their extraordinary capacity to interpret the other's mind.

This represents a peculiar type of intelligence related to understanding mental states such as desires, intentions and beliefs from the other's bodily presence: face, posture and sound. ... The pioneering work of D. Stern in his studies on babies noticed already that the boundaries of self and others are not delineated even in perceptual events, and that being a 'me' and constituting a 'you' are concomitant events. The baby's amazing capacity for empathic response emerges a few hours after birth. (Thompson 2006, forthcoming, p.80)

In other words, the act of cognising the self arises simultaneously with and is dependent on cognising the other. "Intersubjective interaction is the cognition and affectively charged experience of self and other" (Thompson 2006, forthcoming). The depth to which we embody this co-determination is illustrated by studies that show that the bodily expression of genetic traits in children and the properties of their brain activity are related to the degree of love and care they receive from those around them (Savage-Rumbaugh, Fields, and Taglialatela 2001). Varela summarises his concept of intersubjectivity with the following two phrases: "this mind is that mind" or "cognition is generatively enactive, that is a co-determination of Me-Other" (Thompson 2007, forthcoming, p.80).

Not only is our perception of our self dependent on our concept of the other, Varela argues that much of this emotional affective substratum to cognition is primordial, it has affected us before our 'I' has arisen. "Affect is a pre-reflective dynamic in self-constitution of the self, a self-affection in a literal sense. Affect is primordial, in the sense that I am affected or moved before any 'I' that knows" (Thompson 2001, p.80). This process happens on three principal time scales.

The first scale is *emotions* proper, the awareness of a tonal shift that is constitutive to the living present. The second is *affect*, a dispositional trend proper to a longer time (hours or days), a coherent sequence of embodied actions. Finally there is *mood*, the scale of narrative description over a long duration (many days or weeks). (Thompson 2001, p.81)

Varela argues that the pre-verbal or primordial quality of affect makes it inseparable from the presence of the 'other'. To demonstrate why this is the case it is necessary to focus on the bodily correlates of affect, that is, not only our external behaviours but also our corporeal experience of affect. I am linked to the 'other' through both these aspects of my embodiment. The 'other' has a body like mine and is an embodied presence. Both of these aspects of embodied affect are necessary for empathy. The first-person conception of intersubjectivity brings the possibility of

the second-person position to life, in relation to the first-person, through its understanding of the role of empathy.

The term ‘expression’ refers to all forms of the signification of experience (Depraz, Varela, and Vermersch 2003, pp.65-7). Expression is a direct manifestation of experience, “the subjective life of the mind” (Thompson and Zahavi 2007, forthcoming, p.35). Just as the ‘self’ and self-awareness always acknowledge their alterity, that is they include and are mediated by the ‘other’, self-expression, like suspension and redirection, is always an intentional intersubjective action (Depraz, Varela, and Vermersch 2003, pp.68-70; Zahavi 1999, pp.164-166). Expression is intersubjectively open (Thompson 2001, p.15). Expression, and the reception of expression, are, through transcendence, both ‘self-altering’ and intersubjectively ‘other-altering’ (Thompson 2005 p.272). What the second-person researcher perceives is the expressive actions of research participants’ intentional meaningful behaviour (Thompson and Zahavi 2007, forthcoming, p.35). This is not simply their external movement which is then given intention and meaning through inference.

5.8 Empathy

One aspect of concrete intersubjectivity is empathy (Thompson 2001, p.16). Broadly defined, empathy arises out of the intentional processes of consciousness. It is the capacity to act intentionally to gain understanding of another’s experience of their lived body, feelings and emotions. “As a unique kind of intentional act, empathy is directed toward, and thereby has as its intentional correlate, the experience of another person” (Thompson 2005 p.263).

Founded on sense perception, empathy is more than the sum of perception and inference; it involves directly experiencing the other as an expressive intentional being. The task of the phenomenologist is to “analyze the modes or ways in which the other is disclosed as another subjectivity, as well as the intentional structures of consciousness that make this disclosure possible” (Thompson 2007, forthcoming p.570). The active process of empathising with the other “generates a state or situation in oneself that is more applicable to the other’s state or situation than to one’s own prior state or situation” (Thompson 2005 p.264). This is the experience of “feeling led by an experience that is not one’s own, but that is given in one’s experience of another’s expressive bodily presence” (Thompson 2007, forthcoming p.572). Empathy is a ‘self-displacing’ or ‘self-othering’ act (Thompson 2001, p.20).

According to Husserl, consciousness is implicitly open intersubjectively (Thompson 2007, forthcoming p.565). The co-intention or appresenting function of perception, whereby one intends the presence of, for instance, the hidden profiles of objects, provides a demonstration of open intersubjectivity and reflects the role of open intersubjectivity in the formulation of

objectivity. The very concept ‘object’ implies a plurality of subjects (Thompson 2007, forthcoming p.566).

The point is rather that the intentional structure of perception discloses objects as transcending one’s individual consciousness of them in such a way as to imply their presence to and perceptibility by other possible subjects. In this way, the intentionality of consciousness is intersubjectively open, and incompatible with any solipsism that would deny the possibility in principle of a plurality of subjects who view the same world as I do. (Thompson 2007, forthcoming p.567)

This *a priori* openness to the other also underpins the structure of subjectivity (Thompson 2007, forthcoming p.568). In this way, “the self and other enact each other reciprocally through empathy” (Thompson 2007, forthcoming p.565). Thompson provides an evaluation of the similarities between cognitive science, phenomenology and Buddhism with respect to empathy (Thompson 2005 pp.270-275). Buddhism provides a role similar to phenomenology for the active empathic imagination in the decentering of the ego and the understanding of the relation between ‘self’ and ‘other’ (Thompson 2005 p.271). According to Buddhism, “‘self’ and ‘other’ have no independent existence and intrinsic identity but exist only on the basis of conceptual or mental imputation” (Thompson 2005 p.270). Buddhist practices such as mindful awareness, and the cultivation of compassion, illustrate the fact that empathy involves a developmental process (de Waal, Thompson, and Proctor 2005, p.43). Thompson discusses cases where empathy is lacking and encourages the acknowledgement of empathy as a cultivated skill (de Waal, Thompson, and Proctor 2005pp.48-51).

First-person phenomenology considers the concrete practice of empathy to be a central requirement to any science of consciousness. In order to study consciousness, it is necessary to recognise a subject as conscious, which requires a sense of empathy with that subject. Likewise, interpreting a subject’s reported experiences and asking a subject to follow a procedure and report on their experiences assume empathy. “One could even argue that empathy is in certain ways constitutive of consciousness” (de Waal, Thompson, and Proctor 2005, p.44). To achieve an understanding of the role of empathy in consciousness research requires that Husserl’s concept of empathy be refined and incorporated into the experimental context and, conversely, that empathy be considered key to scientific praxis (Depraz and Cosmelli 2003, p.166). As a ‘working experience’, this requires an empathy that is grounded in the lived body.

Empathy involves a spectrum of states (Thompson 2005, p.265). First-person research distinguishes four particular strands within this spectrum (Depraz 2001, pp.172-4; Thompson 2007, forthcoming, pp.579-592). Through prereflective perception and action, empathy exists firstly as affective resonance and sensorimotor coupling (Thompson 2007, forthcoming pp.579-82). This ‘sensual empathy’ is not initiated voluntarily but forms a foundation for the later forms

of empathy (Thompson 2005 p.265). Passive by nature, sensorimotor coupling is grounded in the holistic experience of the lived body of both participants and is based on their resemblance. “Coupling is an associative process through which my lived body and your lived body experience a similar functioning of our tactile, auditory, visual, proprioceptive body-style, of our embodied behaviour in the world, and of our affective and active kinaesthetic habits and acts” (Depraz and Cosmelli 2003p.172). Thompson discusses the evidence for coupling from cognitive science and neurology (Thompson 2007, forthcoming pp.579-82). Recent findings with respect to mirror neurons (Gallese 2001) point towards a biological substrate for this initial form of empathy. Affective resonance occurs when individuals affect each other’s emotional state or when an individual attempts to affect the emotional state of another (Thompson 2007, forthcoming p.582).

The second form of empathy, imaginative transposition, or cognitive empathy, requires the active cognitive act of putting oneself in another’s position (Thompson 2007, forthcoming p.582). Cognitive empathy requires the imaginative act of spatial transposition, a movement that allows the individual to take the mental perspective of the other (Thompson 2005 p.266). Evidence for this kind of empathy is found in developmental psychology (Thompson 2007, forthcoming p.584-5). When this second form of empathy is ‘reiterated’, it becomes the mutual understanding of ‘self’ and ‘other’. This third form of empathy requires the ability to see oneself as an ‘other’, from the perspective of the ‘other’. Thompson refers to this as perspective-taking (de Waal, Thompson, and Proctor 2005, p.39). “Understanding you as an other to me and me as an other to you” requires more than just the first-person perspective and facilitates linguistic interpretation (Thompson 2005 p.267). Evidence for the emergence of this intersubjective perspective appears in infants at a very early age (Thompson 2007, forthcoming p.586-9). The reiteration of empathy required here creates an ambiguity with respect to the body. Although one experiences one’s body from the first-person proprioceptive perspective one is also aware that the other perceives my body from the third-person exteroceptive perspective (Thompson 2007, forthcoming p.589). One cannot escape one’s body as the ‘zero-point’ of reference for the world one inhabits. One perceives this world always through one’s lived body. It is through recognising that one’s body is an object for the ‘other’ that one comes to understand it as an object within an intersubjective world (Thompson 2005 p.268).

Fourthly, empathy is involved in the moral perception of the ‘other’ “as a being who deserves concern and respect” (Thompson 2007, forthcoming p.590). The first and second forms of empathy, involving cognitive and emotional capacity, form the basis for such moral sentiment

(Thompson 2007, forthcoming p.591). All of these forms of empathy are intertwined through the lived body and language.

You imagine yourself in my place on the basis of the expressive similarity and spontaneous coupling of our lived bodies. This experience of yours contributes to the constitution of me for myself, for I experience myself as an intersubjective being by empathically imagining your empathic experience of me. Conversely, I imagine myself in your place, and this experience of mine contributes to the constitution of you for yourself. As we communicate in language and gesture, we interpret and understand each other dialogically. This dialogical dynamic is not a linear or additive combination of two pre-existing, skull-bound minds. It emerges from and reciprocally shapes the nonlinear coupling of oneself and another in perception and action, emotion and imagination, and gesture and speech. In this way, self and other bring forth each other reciprocally through empathy. (Thompson 2007, forthcoming pp.591-2)

This position stresses the need to make all four forms of empathy central to the working experience (Depraz and Cosmelli 2003, p.171). Bringing together this phenomenological basis to empathy and Buddhist understandings of empathy and intersubjectivity the ‘hard problem’ of consciousness or the ‘explanatory gap’ can be viewed very differently. “The problem cannot be ‘how do we go from mind-independent nature to subjectivity and consciousness?’ because, to use the language of yet another philosophical tradition, that of Madhyamika Buddhism, natural objects and properties are not intrinsically identifiable (*svalaksana*); they are identifiable only in relation to the ‘conceptual implications’ of intersubjective experience” (Thompson 2001, pp.20-21). There is no nature external to consciousness because it is only through consciousness that nature is perceived as an object.

Watt (2005) investigates the psychological, cognitive and neurobiological models and definitions of empathy and the relationship between empathy, emotion and social bonds and proposes a model of gated resonance induction of another’s distress for the empathic response.

Toombs (2001) stresses the role of empathy in clinical practice, suggesting that illness as a lived experience needs to be understood on the basis of empathy (Toombs 2001 p.248). It is through acquaintance with our own body that we form the basis for imagining and empathising with the body experience of another. In the case of a physician, what this requires is both the learning and unlearning of bodily normality (Toombs 2001p.254). Toombs comments: “It is not just that medical training results in the ‘unlearning of bodily normality’, but that, for the most part, we remain remarkably unattuned to our bodies (Toombs 2001p.254). In contrast, practices such as mindfulness meditation can be used to enhance an individual’s conscious embodiment (Toombs 2001pp.254-5). The specific skills that Toombs suggests are required to achieve this are empathic listening and a practiced ability to exercise imagination with respect to the lived experience of illness (Toombs 2001pp.255-288). For the present research, understanding the role of empathy acts as a means by which the researcher may be self-reflective.

5.9 Enculturation

Empathy and intersubjectivity intersect at enculturation, that is, “the cultural and historical becoming of human experience within and across generations” (Thompson 2007, forthcoming p.592). Enculturation requires a generative rather than a static or genetic analysis of the ways in which culture constitutes the individual. “Human mentality emerges from developmental processes of enculturation, and is configured by the distributed cognitive web of symbolic culture” (Thompson 2007, forthcoming p.593). Enculturation rejects the dichotomisation of nature from nurture and nature from culture and draws instead on developmental systems theory.

The developmental system of an organism or life cycle is the matrix of resources necessary for its development. Any resource that reliably recurs in each generation and plays a role in reconstructing the life cycle counts as something inherited. Such resources include not simply genes, but many other elements of the organism and its niche, from cytoplasmic components within the cell, which must be passed on with the genes, to symbiont organisms, social structures, and cultural practices. In addition, developmental systems theory rejects the “master molecule” conception of genes: genes are not distinctly informational causes of development different in kind from other developmental factors that do not qualify as informational. Rather than unfolding according to a transmitted genetic blueprint or program, the developmental process of a life cycle reconstructs itself from generation to generation by way of myriad interdependent causal pathways on multiple levels – genetic, cellular, social and cultural. Evolution is not simply change in gene frequencies, but “change in the distribution and constitution of developmental (organism-environment) systems” (Oyama 2000, p.77). (Thompson 2007, forthcoming p.594)

Enculturation places the developmental influence of social structures and cultural practices on a parallel with genes or the biological situatedness of the subject. The elements of ‘nature’ do not precede those of ‘nurture’, rather, they are both sources of informational input into the developmental process and are subject to the influence of each other. In this respect, the concept of enculturation is very similar to the Mahayana Buddhist concept of karma (see section 4.9).

Enculturation begins at conception; it highlights the role of empathy in the learning of communicative conventions such as certain forms of symbolic representation and thought (Thompson 2007, forthcoming p.593-8). Language is intentional and perspectival; it is enacted through imitation and role-reversal (Thompson 2007, forthcoming p.597-9). Thompson comments:

It seems reasonable to hypothesize that the cultural environment of symbolic representation, which provides the scaffolding for the construction of complex cognitive representations and skills, can alter the neural architecture of the developing brain (Donald 2001, pp. 153, 212) ... given this ‘neural constructivist’ viewpoint – and the consilient one of developmental systems theory – it seems reasonable to believe that, as Donald puts it, ‘symbolizing cultures own a direct path into our brains and affect the way major parts of the executive brain become wired up during development. This is a key idea of deep enculturation ... Culture effectively wires up functional subsystems in the brain that would not otherwise exist’ (2001, p.212) ... in phenomenological terms, this power of culture and language to shape human subjectivity and experience belongs not simply to the genetic constitution of the individual,

but to the generative constitution of the intersubjective community. Individual subjectivity is from the outset intersubjectivity, as a result of the communally handed down norms, conventions, symbolic artefacts, and cultural traditions in which the individual is always already embedded. (Thompson 2007, forthcoming pp.600-1)

This process of enculturation occurs on three time scales: phylogenal, historical and ontogenal (Thompson 2007, forthcoming pp.602). Phylogeny and historicity are expressed within the individual's ontogeny. This suggests that language as a communicative convention is embodied, intersubjective, empathic and constitutive of the functional architecture of the brain and of experience. Enculturation suggests that there is a reciprocal relationship between language and experience. I would suggest that deeply enculturated functional architectures of language would be evident in the structure of language.

The semiotics of Algirdas Julien Greimas (1979; 1987) provides one means to study the structure of language, and therefore allows observation of the effects of enculturation. Eugene Gendlin's (1962) theoretical contribution to the understanding of how meaning derives from phenomenality provides a bridge between phenomenal data and semiotics. This bridge is the main concern of the next chapter, providing the means to observe enculturation in action. Enculturation is further explored in the model of action presented in section 12.7.

6. Methodology

The empirical questions must be guided by first-person evidence. (Varela 1996, p.344)

6.1 Introduction

The purpose of this chapter is to explain, building on the approach developed in the previous chapter, the theoretical underpinnings of various aspects of the method employed in this research: textual invariants, saturation, nodes and coding, cluster analysis, and semiotic analysis.

To achieve this goal a brief outline of Gendlin's theory of meaning, including his definition of meaning, felt sense, the role of felt sense in cognition, the relationship between felt sense and symbols, and the intricacy of felt sense will be presented in section 6.2. The connection between semiotics and experience can then be specified. This connection is presented in section 6.9.

Textual invariants, their relationship to phenomenal invariants (first discussed in section 5.2), and the gesture of epoche (first discussed in section 5.5), are discussed in section 6.3. The concept of saturation is defined in section 6.4 through firstly, a discussion of Gendlin's theory of the generation of meaning, secondly, compound meaning, and thirdly, a connection between graph theory and symbolised felt meaning. Epoche and saturation are fundamentally important to the interview process used in this research. The interview process is described in detail in section 7.6.

The formalisation of experience, through semiotic analysis is discussed in section 6.5. Suggestions for other techniques for the formalisation of experience are discussed in chapter 12.

Nodes and coding are defined in section 6.6. How and why nodes can be used to represent experience is explained through a discussion of process-knowledge and intricacy. This discussion is presented in section 6.7. Process knowledge, epoche and Gendlin's theory of the generation of meaning are used in the general model of action presented chapter 12.

Gendlin observes that concepts can retain their implicit intricacy by forming clusters. In section 6.8 the use of cluster analysis for this purpose and to elucidate otherwise not easily visible structures of experience is considered. The practical method of cluster analysis used in this research is described in section 7.9.

The requirements for establishing the validity of phenomenal research data and methods are considered in section 6.10. The application of these to the research is described in section 7.6.10.

6.2 Gendlin's Theory of Meaning: Experience, Meaning and Symbolisation

Gendlin's (1962) theory of the generation of meaning offers a means by which to understand how experience relates to symbolisation. This research examines 'what it is to have the experience of CFS' through an analysis of interview material: the symbolisation of the experience in spoken, recorded and written words.

Traditionally philosophy has understood the generation of meaning as evolving within the conceptual towards explanations of the pre-conceptual. Gendlin's approach reverses this trajectory and takes pre-reflexive experience as the origin of meaning. Gendlin offers a functional definition of meaning: meaning arises from the relationship between pre-reflexive felt experience and its symbolisation. "We formulated "meaning" in experience as a "symbolic function of experience" or "a functional relationship between experiencing and symbols". We found these two terminologies equivalent" (Gendlin 1962 p.184).

Gendlin comments: "experiencing is simply feeling, as it concretely exists for us inwardly, and as it accompanies every lived aspect of what we are and mean and perceive" (Gendlin 1962 p.15). Gendlin's term *experiencing* emphasises the continuity of experiencing as a process and is synonymous with felt sense and felt meaning. Felt meaning is the concretely experienced basis of understanding and is distinct from the verbal and conceptual formulations that only express aspects of such felt meaning. Gendlin writes:

Until recently, there was no established word or phrase for this bodily sensed implying. It was often called "kinaesthetic" but *kinae* means motion, and I need to tell you that you can have it also while sitting still. It was also called "proprioceptive". Etymologically that means sensing oneself. It does not well name "sensing oneself living in interaction in situations". Also, "proprioceptive" is mostly used for sensing one's muscles. (Gendlin 1992, p.200)

Although these references to the body are not adequate to capture comprehensively felt sense, the body's role in felt sense is fundamental.

Gendlin provides an account of how felt meaning is a necessary functional component of all cases of human cognition, including unconscious cognition. Felt meaning is omnipresent and performs specific necessary functions within specific cognitive processes, including symbolisation (Gendlin 1962 pp.63-89).

Gendlin enumerates several basic kinds of relationship between symbols and experience: direct reference, recognition, explication, metaphor, comprehension, relevance, and circumlocution (Gendlin 1962 pp.90-137). The aggregate of these relationships forms the meaning of a set of symbols, or in other words these seven relationships are the basic components of symbolisation. The relationships between felt meaning and symbols are the basis of meaning. Of these kinds of relationship, direct reference, that is "an individual's direct

reference to a present felt meaning” (Gendlin 1962 p.94) provides the basis for the value of Gendlin’s definition of meaning for the investigation of experience. Direct reference allows the study of particular experiences by connecting such experiencing to its symbolisation. Direct reference, recognition, and explication are one-to-one relationships between symbols and experience. Metaphor, comprehension, relevance, and circumlocution are more complex, many-to-many relationships between symbols and experience. None of the basic relationships can be considered arbitrary, despite their intricacy and complexity, because they all rely on the specificity and exactitude of the underlying felt meaning (Gendlin 1962 pp.90-137).

This is not an exhaustive list of the possible relationships between symbols and experience. Gendlin demonstrates a procedure for inductively creating new kinds of relationship, giving an infinite set of possible relationships. An attempt to be exhaustive would therefore be impossible. Nevertheless, those relationships in use in any given situation are finite in number, discoverable and definable. Finite in number because there are only so many symbols in use, discoverable because semiotics provides a systematic method for discovering the relationships in use and definable because semiotics is a constructive method that provides a symbolisation of any relationship that can be discovered semiotically (Gendlin 1962 pp.138-172).

Symbolisations are always an approximation to the full complexity and ‘analogue’ nature of felt meaning, which Gendlin calls intricacy:

Since intricacy is not separable from [conceptual] distinctions, and since it is somewhat different with different distinctions, you might wonder what independence from them it can have. You will see that intricacy has an order of its own because it always responds with an unavoidable exactitude that vastly exceeds what could possibly follow from the distinctions. So it is wrong to say that they – the distinctions - made (found, lifted out, synthesized, differentiated ...) what comes. That attributes the intricacy to *them*. (Gendlin 1992, p.195)

Although conceptual distinction can bring forth intricacy into consciousness, the intricacy of experience is not derived from the conceptual. Intricacy is an aspect of the pre-reflexive that exceeds and is vital to the formation of the conceptual. The body is the source of the ‘coming’ or implying that is necessary for the unfolding of intricacy. The body, therefore, plays a vital role in both pre-reflexive experience and the conceptual.

Gendlin’s IOFI principle demonstrates how his functional definition of meaning can be used to ask methodological questions (Gendlin 1962 pp.173-204). The IOFI principle can be stated: any meaning taken to be an example of a broader category of meaning is itself contained in that category. Equivalently, any specified meaning is an instance of a methodological category in either a) any relevant aspect of itself or b) any role it takes in a discourse. Semiotics is a tool for determining the role the symbolisation of a specified meaning plays in a discourse.

Where semiotics clarifies the role of a symbol in a discourse, the IOFI principle binds the symbol to a specified meaning. Combining semiotics and the IOFI principle delivers not merely the semiotic role a particular sign plays in a discourse, but rather, the functional role a specified meaning plays in the network of meanings of the discourse and its context. The IOFI principle can be utilised to provide the connection between semiotics and experience.

What this implies is that there is a functional relationship between the structures that emerge from a semiotic analysis of discourse and the structures of the specified experiencing that was symbolised in the discourse. In other words, semiotic analysis can be used to discover aspects (and structure) of the experience underlying any discourse. The functional relationship between semiotic and experiential structures can be extremely complex, it should not be assumed that this relationship is necessarily a straightforward equivalence. If it were the case that this relationship was a straightforward equivalence, this would imply that the symbolisation was a direct representation of the structure of the experience; although this can happen, for example in direct reference, it cannot be assumed.

6.3 Epoche, Phenomenal Invariants and Textual Invariants

The analysis process employed in this research identifies textual invariants in the interviews with the research subjects, both during the interviews and in the interview transcripts. This section clarifies how textual invariants relate to phenomenal invariants and how phenomenal invariants are generated through the gesture of epoche.

All approaches to the first-person study of experience require a systematic procedure for accessing the phenomenal domain concerned (Depraz, Varela, and Vermersch 2003, p.6). The interview method employed in this research utilises epoche in the evocation and elicitation of what it is to experience CFS. Epoche is one procedure for finding a symbolisation that accurately and authentically reflects a specific felt meaning. “What we found was the following: epoche and intuitive evidence form the minimal but self-sufficient cycle of the reflecting act. That means they call for one another: epoche is naturally completed by an intuition that crystallizes for the subject and which serves as strong internal evidence; this evidence is prepared for and qualified by a gradual process of completion that has its own quality of suspension” (Depraz, Varela, and Vermersch 2003 p.24). Many of these symbolisations may simply be thoughts or actions that do not necessarily take linguistic form. A phenomenal invariant can be defined as a symbolisation that accurately and authentically reflects a specified felt meaning, and therefore, the act of epoche generates phenomenal invariants.

By contrast to the previous descriptive definition of phenomenal invariants (see section 5.2) as the “categorical features of experience that are phenomenologically describable both

across and within the various forms of lived experience” (Lutz and Thompson 2003, p.32), this definition is productive, in that it arises from the specific procedure of epoche. Phenomenal invariants are not textual invariants.

Textual invariants, in contrast to phenomenal invariants, are semiotic patterns in symbolisation (for instance, text or discourse), which exist because they are the symbolisations of phenomenal invariants. Instances of textual invariants are not necessarily identical repetitions of the same symbols, but are semiotically equivalent. Each instance may vary, but the semiotic equivalence is due to the underlying phenomenal equivalence; the variations are merely due to the goodness of fit (or lack thereof) between symbols and felt sense in each case, and the fact that the language is underdetermined by the phenomenology. That is to say that there are many ways to symbolise any particular experience and the intricacy of that experience is not necessarily comprehensively represented by an individual symbolisation.

Textual invariants form the basis of the definition of saturation and process of coding, both of which are necessary to the large scale semiotic analysis of experience used in this research. Saturation is considered in the next section, and the large scale semiotic analysis of experience will be developed in later sections.

6.4 Compound Meaning, Graphs and Saturation

Gendlin’s theory of the generation of meaning is enlisted in this section for an explanation of compound meanings and a connection between graph theory and symbolised felt meaning. This provides a definition of saturation as applied to interview material and the interviewing process.

Gendlin’s definition of meaning implies that, a set of relations between a set of meanings is itself a meaning.

Since meanings can be seen as relations between meanings, a creative process is possible in two directions: a given experienced meaning may function in (a) creating relations to (new aspects of) other experiences; (b) creating other experiences between which this given one is a relation. (Gendlin 1962 p.160)

Further meaning can be derived from existing relations between meanings, that is to say, these relations are generative of compound meanings. A mathematical graph is merely a set of nodes combined with a set of relations between these nodes. If the nodes are taken to refer to meanings, then the graph is itself a symbolisation of a compound meaning, moreover so is any subset of the nodes and all the relations between nodes in that subset (a subgraph). This implies that a large graph of meanings both refers to and is a generator of an enormous number of meanings. A graph is an alternative symbolisation of a set of meanings.

In effect, the interview process is a semiotic process of traversing the graph of connections between readily apparent textual invariants up to the point where there are no links that point towards unexplored or new invariants of experience. When this process has achieved a complete traversal of the graph symbolizing the overall experience, saturation of the symbolization of experience has been achieved. Saturation has occurred when further data fails to produce any new evidence of phenomenal variability beyond that which has been established. A saturated interview text is, therefore, a best possible approximation to an authentic symbolisation of the experience.

Given that during an interview the researcher is unlikely to be able to identify textual invariants at the rate at which they are presented, it is likely that some textual invariants will not be identified during the session. This implies the importance of reviewing the interview material after each session. It also suggests that it is important to design an interview process that is iterative from the outset, creating the option of further sessions until reviews show saturation has been achieved.

The degree to which and rate at which saturation is achieved is limited by the following: the skill of the interviewer to induce and elicit reports of experience, and the skill of the interviewee at *epoche*, evocation, elicitation and reporting. Saturation is also limited by the statistical limits to the information capacity of a finite set of symbols in the medium between interviewer and interviewee. In other words, there is only so much that can be said in limited time or space, with a particular set of symbols. Saturation of discourse occurs at the point of maximum mutual information between interviewer and interviewee given the limited communication capacity of the medium in use (voice, video, gesture etc.). Beyond the point of saturation, further communication only results in duplication. Without saturation, further analysis of experience will be difficult, as the presence of unspecified relationships will leave aspects of the analysis underdetermined.

6.5 Semiotic Analysis and the Formalisation of Experience

A process of formalisation is required in order to generate a model of experience that can be validated. In this research, I treat the participants' external behaviour of expression through verbalisation and the resultant interview transcripts as, in Varela's terms (2003, p.9-10), a trace or manifestation of the participants' internal mental life. This requires the assumption that an accurate transcription process is semiotically neutral, in other words the transcript is equivalent to the interview for the purpose of the *post-facto* analysis. That process is a multi-step semiotic analysis that uses coding, graph-theoretic clustering and interpretative input by the researcher at

each step to elucidate meanings and aspects of the CFS experience that are not readily apparent in the raw data.

Several steps of the analysis process towards a formal model of the experience involve transformations from one form of description to another. Firstly, transcription of the subjects' spoken accounts into text, secondly, coding of the interview transcripts into nodes, thirdly, the clustering of nodes and the graphical presentation of those clusters, fourthly, semiotic analyses of the node contents from clusters or groups of nodes, and finally, theoretical explication providing a model for the experience. Each of the transformations in the analysis process is intended to be meaning preserving. The descriptive forms, such as nodes, node labels, and graphs, used at each step of the analytic process are chosen to facilitate the researcher's reflection on the material.

6.6 Nodes and Coding

Given a graph of textual invariant nodes derived from a saturated interview process, it is possible to enlist further techniques from graph theory to assist semiotic analyses of experience. This requires the preparatory step of coding interview transcripts into nodes. Nodes and coding are defined in this section.

Coding involves the semiotic process of identifying and collating into nodes, passages of interview text that describe textual invariants. The labels given to the nodes refer to the textual invariants described by the interview passages collated at that node. Nodes are simply containers for interview material that symbolises textual invariants. These symbolisations coded to a node constitute a specified meaning. According to the IOFI principle this meaning can also be considered a methodological category. The label attached to the node directly refers to the specified meaning and the methodological category that this specified meaning symbolises. Therefore the node labels also directly refer to the experience underlying the textual invariant that generated the node.

6.7 Process Knowledge and Intricacy

Adequate tools for the examination of experience need to reflect the fact that experience is an infinitely varied continuous process. Intricacy and a dynamical systems view of process provide these tools.

Gendlin's (2004) concept of process-knowledge suggests that considering any experience in terms of atomistic, rigidly defined discrete components is a potentially flawed approach. In effect, any experience is a complex dynamic system. Gendlin comments: "there are precise distinctions between different kinds of processes, precise ways to identify whether a given kind of process is occurring or not, the precise conditions under which it can be brought about, and its

precise results” (Gendlin and Johnson 2004 p.3). Despite not being constituted from discrete components, such complex dynamic systems do have multiple processes and subprocesses that can be characterised and, in combination, describe the overall process. Nodes used to refer to any experience, likewise, do not refer to discrete components. The nodes are better understood as referring to the eigenstates, or characteristic states, of the ongoing processes involved in the experience. The textual invariants that refer to the content of these nodes are the symbolisations of the eigenstates underlying them.

The coding process requires that the researcher observe the symbolised experience offered by the subjects and recorded in the interview transcripts. This process creates felt meanings, and the researcher is then required to symbolise those felt meanings into coding decisions, and further symbolise those coding decisions into node labels. As I coded the interview text it was as if the nodes arose from the initially undifferentiated discourse in the same manner as Gendlin describes the specification of felt meaning into language. This meta-analysis of the articulated experience seems, therefore, to follow the same specification process as underlies the subjects’ explicitation of their experience. Both are symbolisation specification processes. The process of symbolisation is the process of identifying and calling out symbols that combine to a similarly weighted collection of eigenstates. This involves a very precise transformation since, as a matter of mutual constraint, the symbolisation process is specified on one side by felt meaning and on the other by the structure of language, that is to say, by enculturation and, as will be discussed below, by semiotics, particularly the semiotic concepts of generation, generative grammar and the generative trajectory.

Since a set of relations between a set of meanings is itself a meaning, the same is true of nodes, and the specified meanings that they represent. Observation of the relationships between nodes can give rise to new codes that create new composite nodes. Nodes representing the more subtle or complex aspects of the experience arose in this way.

Symbolisation always involves the underlying implicit intricacy of experience. The symbolisation process appears to produce discrete entities from this intricacy. Prior to symbolisation, however, these discrete separations did not exist in all instances, they functioned within a pre-separated multiplicity.

When concepts retain implicit intricacy, they form a cluster. Each says more about the others. This “more” is not a fuzzy excess of form. Each lets us think—in exact ways—how more functions than what was already formed. (Gendlin 2002 p.92)

One purpose for deriving the experiential clusters from the relationships between the nodes was to preserve some of this pre-separated multiplicity in the examination of the structure of the CFS experience.

What Gendlin describes in pre-reflective experience as intricacy, Maurel (Maurel 2009) describes in evocation as specificity. Gendlin provides numerous approaches to the investigation of this intricate exactitude of experience (Gendlin 1962, 1978, 1986, 1992, 1996, 2002). He is particularly concerned with how this intricate exactitude enters into symbolisation from the body. For Gendlin (2002) the ‘...’ is the space in which the letting come of epoche occurs. The ‘...’ is the moment in which new meanings are created as what is implied in our embodied experience is called forth into symbolisation. This precise implicit intricacy is what is exhausted in the process of saturation described in section 6.4.

In his in-depth discussion of the theoretical and methodological issues surrounding introspection Vermersch comments:

A second complementary hypothesis is that all these retentions are linked, interwoven and connected by resonances over distances, and associations of all kinds. And that each moment recalled in the evocation mode takes into view everything that is linked to it and can be seized provided that the view is shifted inside what is given. For this intuitive donation elicited by evocation will open up possibilities provided by the continuous interweaving of all the components of the lived experience. This means that each recollected lived element can give rise to and/or be the object of the placing into relationships with everything which is linked to it, by [simple] contiguity or by remote reference. ... The practical question is then no longer recollecting, but discerning in what has already been recollected everything which is attached to it, and whose description may be relevant. (Vermersch 2009, p.41)

Since there are semiotic relationships between the contents of all the nodes, these nodes and their semiotic relationships form a graph, which is therefore another form of symbolisation of the authentic experience. In Vermersch’s terms, this graph records and links what is attached to the experience recollected in each node.

6.8 Cluster Analysis

Gendlin’s observation that concepts can retain their implicit intricacy by forming clusters inspires the use of cluster analysis in this research. Cluster analysis can also clarify the structure of the experience considered.

Cluster analysis provides one important mathematical method for apprehending structure in graphs that are too large or interconnected for direct inspection. A cluster analysis divides a graph into clusters, each of which is a subgraph that contains a portion of the structure of the original graph that is strongly interrelated by some criteria that must be specified for a particular cluster analysis. The clustering process applied to the coded interview data in this research is a meaning preserving transformation since it merely guides a re-sequencing of the data. This can be seen by the fact that the clustering process extracts strict subgraphs from the graph representing the overall experience. If the graph being divided into clusters is a symbolisation of some compound meaning, so is each subgraph. Moreover, the meaning symbolised by each

subgraph is present in the implications of the original graph, although this is unlikely to be apparent by inspection. Cluster analysis can make subtle meanings far clearer and more explicit than they were in any previous step of the process.

6.9 Using Greimasian Semiotics as a Tool for the Analysis of Phenomenal Data

In understanding the gesture of communication, be it in the form of speech or otherwise, the communicators' intention is always to create the desired experience in the audience. Just as one creates and experiences one's self as the communicator, one co-creates the 'other' as audience. It is this co-creative intention that shapes the communicative action. Communication, such as conversation as a form of communicative action, is an iterative process of achieving and refining shared conscious experience. A model for the intersubjective structure of communication is proposed in chapter 12.

Greimas does not presuppose a model for the structure of communication, rather he is concerned to establish the conditions of possibility for the communication process, including those which are structural in nature (Schleifer 1987, p.xviii). This suggests that Greimas's approach to semiotics follows the tradition established by Louis Hjelmslev rather than the pragmatics of Charles Sanders Peirce (Schleifer 1987, p.xxii)²⁵. Like Hjelmslev's concern to establish a theoretical framework for a semiotic theory, Greimas is concerned with showing from first principles how semiotics is possible, whereas Peirce is concerned with axiomatising semiotics in terms of formal logic (Nöth 1990).

Greimas's approach is also similar to that of Kant. Norris comments:

Kant sought to ground our knowledge of the world in a structure of concepts and categories whose validity was proved beyond reasonable doubt by the fact that, quite simply, we could not begin to *think* without them. But he also insisted – as against the transcendental idealists – that pure reason must acknowledge its limits and not run wild in speculative problems of its own abstract devising ... concepts should always correspond to some element of intuitive knowledge or concrete perception. 'Intuitions without concepts are blind; concepts without intuitions are empty'. (Norris 1987, p.xii)

Greimas's methodology is similarly both inductive and deductive. He draws on the explanatory power of theoretical constructions such as model and structure whilst also insisting that such theorisation needs to remain harnessed in the service of accounting for the concrete intuitions of the phenomena of meaning. "The utmost that theory can do, Greimas writes, is 'continue to take cognizance of that vision of the world in which signification and the conditions of the signification are found to be entangled'" (Norris 1987, p.xiii). This requirement to return to the concrete promotes the constant renewal of structure and model; they are in no sense assumed to

²⁵ In the history of modern semiotics, Peirce is the major figure of its philosophical branch.

be static or absolute. Requiring an constant returning to the concrete also sustains a living connection between the pragmatic and the theoretical. Greimas suggests that meaning exists and is produced only in its constant formation and transformation: “meaning, in the sense of the forming of meaning, can thus be defined as the possibility of the transformation of meaning” (Jameson 1987, p.x). Akin to the neurophenomenological explanation of experience (Varela 1996, p.346), it does not make sense to Greimas to imagine any static state of meaning. Experience and meaning are continuously co-generative.

Greimas perhaps anticipates the need for a naturalised phenomenology, such as that which the neurophenomenological methodology aims towards, when he writes of his approach that it promises to “throw a bridge across the misty zone of the world of the senses and the effects of meaning by someday reconciling, perhaps, quantity and quality, man and nature” (Greimas in Norris 1987, p.xiii). With this gesture, Greimas acknowledges the need for a concept such as enculturation with its reformulation of the distinction between the natural and the cultural (see section 5.9). The nomenclature that Greimas developed in *Semiotics and Language: An Analytical Dictionary* (1979) provides the present research analysis with the formal dynamical tools (Lutz 2002a, p.149) from which a model for the structure of signification within the participants’ narratives can be fashioned. The Greimasian nomenclature provides the basis for a clear procedure or technique for accessing and analysing the phenomenal domain of concern (see section 5.5).

Greimas is concerned with the phenomenality or experience of meaning. “For Greimas, then, the ‘nature’ of meaning is *phenomenal*; it ‘exists’ as the felt sense of its presence, a signifying *whole* beyond the limits of the sentence, or the felt sense of its negated presence, the ‘nonsense’ and ‘bewilderment’ of fragmented sense” (Schleifer 1987, p.xix). This phenomenal focus makes Greimasian semiotics a tool particularly compatible with first-person psycho-phenomenological and neurophenomenological analysis of experience. Greimas defines his semiotic project for the social sciences as principally heuristic. He is concerned to create a scientific discourse that can provide hypothetical models of signification that can be confirmed, invalidated or falsified. The role of semiotic theory, for Greimas, is to bring a homogeneity or coherence to these models. These models function as intermediary steps toward a scientific account of meaning (Greimas 1987, p.xxvi). Greimas sees science as a practice or process rather than a completed organization of knowledge (Perron 1987, p.xxxi).

Greimas considers meaning, like experience, to be a ‘given’ (Schleifer 1987, p.xviii) about which nothing can be said. Meaning is the guiding thread from which a Greimasian reduction starts and to which it links back (see section 5.4). The ‘nonobjectifiable’, irreducible givenness

of meaning is an explanandum in its own right (see section 5.4)(Jameson 1987, p.ix). Meaning is the reception of ‘reality’ rather than its expression. For Greimas to ‘account for’ or ‘make sense’ of meaning is to analyse meaning through its effect, the positive and negative meaning-effects of a signifiatory system, regardless of the form of its signification. Schleifer comments: “to conceive of meaning as phenomenal is to make these ‘conclusions’ about signification themselves subject to accounting in terms of what he [Greimas] calls ‘determinable and, in large measure, determined’ connections among the phenomena of signification” (1987, p.xix).

The connections or relationships between the elements of signification and that which is signified are no more effectively illustrated than in Greimas’s semiotic square (see Figure 1). The relationships of opposition or contrariety, contradiction and implication or complementarity principally describe ‘the discursive effect’, meaning-effect, or force of signification, the concrete or semantic, rather than purely the syntactic or logical operation through which effect is produced. In this way, a Greimasian analysis provides a ‘descriptive articulation’ of meaning that is semiotically produced (Schleifer 1987, p.xxii).

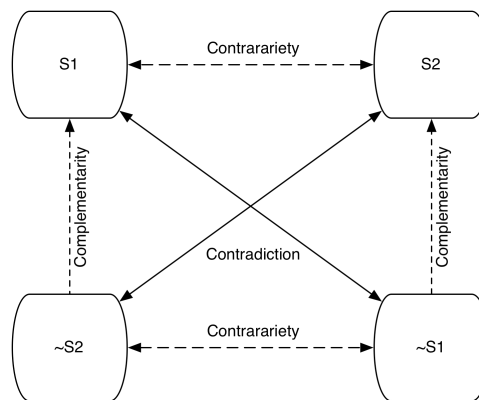


Figure 1: The Semiotic Square

Equally, as an example of the Greimasian nomenclature, the semiotic square²⁶ illustrates how Greimas draws directly on mathematics and symbolic logic in his formulation of models for semantics (Jameson 1987, p.vi). “Description is thus thought of as the construction of a network of relations by the identification and naming of both the observed relations and their points of intersection or disjunction” (Perron 1987, p.xxvi). A descriptive network is therefore a graph composed of the set of arcs of potential semiotic squares amongst terms of the phenomenal

²⁶ “1. By **semiotic square** is meant the visual representation of the logical articulation of any semantic category. The elementary structure of signification, when defined – in a first step – as a relation between at least two terms, rests only on a distinction of opposition which characterizes the paradigmatic axis of language. It is, consequently, adequate for the establishment of a paradigm composed of n terms, but it does not thereby allow for the distinction, within this paradigm, of semantic categories founded on the isotopy (the “family relations”) of distinctive features which can be recognized therein. A typology of relations is necessary, which will make it possible to distinguish intrinsic features, those which constitute the category, from those which are foreign to it” (Greimas and Courtés 1979, p.308). For a more detailed description of the semiotic square see Greimas and Courtés (1979, pp.308-11).

domain under analysis. In a sense, such a descriptive network is a more general, extended, semiotic square. “The formal characteristics of the semiotic square are founded on a dynamic topology of places and connections and not upon a static logic of terms and connections” (Perron 1987, p.xxix). The implication of the terms ‘dynamic’, ‘place’ and ‘intersection’ is that the semiotic square is to be interpreted in a geometric sense, as the basis for a continuous space of potential terms. For example, Greimas distinguishes between strengths of conflicts between terms in a semiotic square (Greimas 1987, p. 57). By extension, strengths of relations in a descriptive network can be interpreted geometrically as distances in a high-dimensional semiotic space (potentially one with a complex topology).

It is possible to use the methods of mathematical graph theory to model the topology of phenomenal domains with very large numbers of isotopes, since the graph theory methods merely rearrange already qualitatively identified semiotic relations. Such a graph represents, in the weak sense of representation (see section 4.12), the relationships in question. This is consistent with the Greimasian understanding of the concept of isotopy²⁷, derived from its Greek roots *isos*, meaning same and *topos*, meaning place. “In its syntagmatic²⁸ extension, an isotopy is constituted by all those textual segments which are connected by one contextual seme”²⁹ (Nöth 1990, p.319). In this sense, an isotopy identifies a localised subset of a descriptive network. This can be any of a single node, a subset of nodes or an identifiable cluster of nodes.

There is a strong parallel between Greimas’s generative trajectory as his explanation for the production of meaning and the concept of emergence. Resonant with the reciprocal relationships between experience, symbolisation and meaning enumerated by Gendlin, Greimasian analysis acknowledges that meaning exists and emerges from levels both higher and lower than the sign (Nöth 1990, p.315). Greimas suggests that the generation or production of meaning follows a trajectory from the “simplest to the most complex, from the most abstract to the most concrete” (Greimas and Courtés 1979, p.132). For discourse, Greimas puts forth three

²⁷ “1. A.J. Greimas has borrowed the term **isotopy** from the field of physics and chemistry and has transferred it to semantic analysis by giving it a specific signification in view of its new field of application. As an operational concept isotopy at first designated iterativity along a syntagmatic chain of *classemes* which assure the homogeneity of the utterance-discourse. From this point of view it is clear that the syntagm joining together at least two *semic* figures may be considered the minimal context necessary for establishing an isotopy. Such is the case for the *semic* category that subsumes the two contrary terms. Taking into account the trajectories to which they can give rise, the four terms of the semiotic square are called **isotopys**. 2. With regard to the generative trajectory of the discourse and the distribution of its components, we distinguish between the **grammatical isotopy** (the syntactic isotopy, understood in semiotic terms) with the recurrence of categories pertaining to it, and the **semantic isotopy**, which makes possible a uniform reading of the discourse as it results from the partial readings of the utterances making it up and from the resolution of their ambiguities which is guided by the search for a single reading” (Greimas and Courtés 1979, pp.163-4).

²⁸ “When any knowable object is semiotic in character, it can be perceived either as system or as process – its two fundamental aspects. In such a case, the term **syntagmatic** is used to designate the process” (Greimas and Courtés 1979, p.327).

²⁹ “Seme commonly designates the ‘minimal unit’ of signification” (Greimas and Courtés 1979, p.278).

“loci of meta-semiotic interpretation and construction: semio-narrative structures, discursive³⁰ structures, and textual structures” (Greimas and Courtés 1979, p.133). Textualisation is the ‘putting-into-text’ of the discursive and semio-narrative structures and constitutes an area of independent research (Greimas and Courtés 1979, p.133). Semio-narrative structures include the fundamental or deep and narrative or surface levels of syntactic and semantic content (Greimas and Courtés 1979, pp.133-4). Discursive structures are constructed from discursive syntax, comprising of actorialisation³¹, temporalisation³² and spatialisation³³, and discursive semantics including thematisation³⁴ and figurativisation³⁵ (Greimas and Courtés 1979, p.134). These processes are layered out from fundamental syntax and fundamental semantics; they are iterative processes to construct meaningful discourse. Perron comments: “signification, to the extent that one seeks to find in it an object, appears as an articulation of stable fundamental relations; it can also be represented dynamically, if one considers it as an apprehension or production of meaning by a subject” (Perron 1987, p.xxx). That is to say that nomenclature and notations such as the semiotic square provide clear definitions of stable fundamental relations whereas the generative trajectory is a phenomenological theory of the dynamic emergence of meaning in communicative action. In other words the generative trajectory tracks the path taken by the enaction of communication. Synthesising the work of Gendlin, Greimas, enactive cognitive science and first-person psycho-phenomenology potentially provides a generative conception for the embodied

³⁰ “1. In the first perspective, the concept of **discourse** can be identified with that of semiotic process. In this way the totality of the semiotic facts (relations, units, operations etc.) located on the syntagmatic axis of language are viewed as belonging to the theory of discourse. When one has in mind the existence of two macrosemiotic systems – the “verbal world” manifested in the form of natural languages, and the “natural world” as the source of non-linguistic semiotic systems – the semiotic process appears as a set of **discursive practices**: linguistic practices (verbal behavior) and non-linguistic practices (signifying somatic behaviour manifested by the sensory orders). When linguistic practices alone are taken into consideration, one can say that discourse is the object of knowledge considered by **discursive linguistics**. In this sense discourse is synonymous with text. ... On the other hand – by extrapolation and as an hypothesis which seems to be fruitful – the terms discourse and text have also been used to designate certain non-linguistic semiotic processes (a ritual, a film, a comic strip are then viewed as discourses or texts). The use of these terms postulates the existence of a syntagmatic organization undergirding these kinds of manifestations” (Greimas and Courtés 1979, p.278).

³¹ “What characterizes the procedure of actorialization is that it aims at establishing the actors of the discourse by uniting different elements of the semantic and syntactic components”. (Greimas and Courtés 1979, p.8)

³² “Temporalization consists, as its name implies, in producing the meaning effect ‘temporality’ and in thus transforming a narrative organization into a ‘story’” (Greimas and Courtés 1979).

³³ “In the overall generative trajectory, **spatialization** appears as one of the components of discoursivization (*i.e.*, the putting into discourse of deeper semiotic structures). First, it comprises procedures of spatial localization, which can be interpreted as operations of disengagement and engagement, carried out by the enunciator in order to project out from itself and apply onto the utterance-discourse a more or less autonomous spatial organization that serves as a framework for the inscription of narrative programs and their concatenations. Spatialization also includes procedures for spatial programming, thanks to which a linear disposition of partial spaces (obtained through localizations) is realized; this disposition conforms with the temporal programming of the narrative programs” (Greimas and Courtés 1979, pp.306-307).

³⁴ “In discursive semantics thematization is a procedure – still relatively unexamined – which first takes over the values (of fundamental semantics) that are already actualized (in junction with subjects) by narrative semantics. It then, in a way, spreads them out, with various degrees of concentration, in the form of themes, in the narrative programs and trajectories. Thematization thus opens the way to possible figurativization of themes. Thematization may either be more focused upon the subjects, objects, or functions, or else be equally spread out over the different elements of the appropriate narrative structure” (Greimas and Courtés 1979, p.344).

³⁵ “The discourse is said to be figurativized at the moment when the syntactic object (0) receives a semantic investment which will permit the enunciatee to recognize it as a figure, as an ‘automobile’ for example: SUO (: automobile) v (: power). The discourse which expresses the quest for the automobile, the exercise and, possibly at the end, the recognition by another of the power which it allows to be manifested is a figurative discourse” (Greimas and Courtés 1979, pp. 118-9).

co-generative production of experience, meaning and symbolisation. That an acknowledgement of generative process is also therefore necessary to the functional definition for the validity of phenomenal data, follows from the above and is discussed below.

6.10 Establishing the Validity of Phenomenal Data

For phenomenology to be a science, researchers need clear criteria for the validity of results that are compatible with the scientific method. These criteria also need to be compatible with the constraints and context of phenomenological research.

What we are witnessing here is the emergence of a new conception of the validity of a description: this validity is no longer measured in terms of 'truth', of representative exactitude, or adequacy in relation to a pre-existing experience, but according to the manner of its genesis, the quality of contact with the experience in which the description originates, and the remoteness of its source. (Petitmengin 2006, p.257-8)

Truth, here, is not a question of establishing a direct correspondance between data and experience. Instead, it is the process with which the data is generated that establishes its adequacy. Based on the concepts of performative consistency and reproducibility, this conception of validity is no different to the conception of validity used in the physical sciences.

Performative consistency consists of an agreement among (a) the theories, (b) the construction of devices and the understanding of their functioning, (c) the theoretical guidance of measurements, and (d) the results. (Petitmengin and Bitbol 2009, p.391)

Performative consistency is the basis of reproducibility, since these are the factors required for the reproduction of data. In the case of this research, the devices (or instruments) used are introspection and interview techniques including epoche, and formalisation processes such as semiotic analysis. Theoretical guidance of measurements includes such processes as the application of semiotic analysis in interviewing to guide interviews to saturation. Theories and results are comparable by their structures. That is to say, terminology and presentation may vary greatly among theories with the same underlying structure. Other chapters are concerned with the presentation of the theories and results of the present research.

There are three levels of validation possible in the programme, idiographic validation, intersubjective validation, and neurophenomenological validation. Idiographic validation can be established through a set of objective criteria showing the subject's level of contact with experience, which establishes the authenticity of the description.

The validity of a description cannot be assessed according to its ability to reproduce the described *content*, but according to the quality of its own production *process*. More generally, we are witnessing the emergence of a new conception of the validity of a description, which cannot be measured in static terms of correspondence to experience, but in dynamic terms of authenticity of the process of becoming aware and describing. Whether they are objective or subjective, the criteria of validity we have do not inform us about the

adequacy of the description content, but about the subject's level of contact with experience. The validity of a description is not evaluated by comparing it with its hypothetical 'object', but according to the authenticity of the process that generated it. (Petitmengin and Bitbol 2009, pp.389-90)

The idiographic validity of the data in this research is established through the iterative interview method employed, giving multiple reproductions of elicited experience and saturation to ensure completeness.

Vermersch observes: "sooner or later, the complement of all research on the living subject must also be able to say what he is living, what he is experiencing, in short everything of which he is already or can become reflectively conscious" (Vermersch 2009 p.21). A thorough understanding of the acts of retrospective introspection and verbalisation are critical to this endeavour because it is this understanding that allows the researcher to guide the research subject and to assess the integrity of the data gathered.

The basic structure of the act of retrospective introspection and verbalisation in the research context has three elements: V1, V2 and V3. Previously described as L1, L2, and L3 (Gallagher and Varela 2003), V1 refers to the lived experience that is referenced in the introspective act whereas V2 is the act of evoking, reflecting on or becoming aware of V1. The act of V2 makes verbalisation possible and "has the status of an instrument" (Vermersch 2009 p.29). For the research community to develop the instrument V2 it is necessary to reflect on V2: this reflection is V3. Each research event provides an opportunity to reflect on V2 and the basic structure of the process of becoming aware of the pre-reflexive content of experience.

Within the context of the explication interview, Vermersch describes contact as follows:

Intuitive seizing, authentic contact with the lived experience – whether it is in the immediate or later past – then becomes the privileged act producing the transition to reflective consciousness, it is by this means that is carried out the reflection of what has been lived in the mode of consciousness in action. And this is what makes the quality of authenticity of this contact so important for the production of faithful introspection. (Vermersch 2009 p.37)

Contact establishes the relationship between the reflexive and the pre-reflexive. In this context, contact is what gives access to the pre-reflexive, it is the act of transition between these modes of experiencing.

This reflection is also necessary during the research interview. In my experience, when I am in the second-person position in the role of a researcher, I am continuously engaged in reflecting on my experience of witnessing the research subject whilst the question "is this subject participating in V2" is continually in mind. This ensures the integrity of the data gathered.

Intersubjective validation relies on the reproducibility of the research process and comparison between subjects: "the researcher who investigates lived experience does not have

access to the experience of the subjects he interviews, but he has access to the descriptions they produce. And the descriptions of a given *type* of experience are reproducible (on the condition that one knows the operating mode)” (Petitmengin and Bitbol 2009, p.390-1). In this research intersubjective validity is established through interviewing multiple subjects in each of the subgroups examined.

Neurophenomenological considerations can also suggest the validity of phenomenological data: “finally, the fact that using a given experiential structure may guide neurological analysis and help to discover original structures in the [neurological] data, is a strong confirmation criteria of the validity of this experiential structure” (Petitmengin and Bitbol 2009, p.397). In other words, neurological and phenomenal data both mutually constrain models derived from them, and each can direct the researcher in gathering data by the other’s means. If this process of co-determination is productive, this strongly suggests the validity of both neurological and phenomenal data. In this research, neurological findings from published research on CFS are tentatively compared to the phenomenological findings of this research in chapter 12, particularly with respect to the underlying structure of the illness experience as it pertains to action. Further, findings on the neurology of action are used to propose a theory of the illness process that is consistent with the neurological observations.

6.10.1 Recovery and the Question of the Reporting of Experiences in the Past

It is not possible to ask ill subjects to describe a personal experience of recovery as they have not had this experience. Studying subjects who have recovered, either spontaneously, or by developing their own treatment, potentially provides valuable information about how recovery occurs. Further, this data could provide insight into the nature of the illness experience and contribute towards the development of a treatment programme.

Assessing the viability of data derived from recovered participants requires ensuring such data would not be erroneous. If the research data was likely to be adversely affected by the processes of memory, for instance, this could lead to distortions being introduced. There are two reasons why such an objection does not apply.

Firstly, the present research involves introspective data, rather than memory. What the explication interview accesses is a quality of evoked experience that is cognitively different from memories or purely mental reflections on past experiences. “If introspection was only a question of memory, just the fact of remembering what one experienced which was conscious, there would be no research question. Spontaneous practice shows that it does not function so simply, and that the immediate recollection of one’s own lived experience is poor, anecdotal, and soon exhausted” (Vermersch 2009, p.34). Undoubtedly, the research subject has conscious

recollection of the aspects of experience that they are already conscious of. What is discovered, or brought into contact, through the gesture of retrospective introspection or evocation, however, are aspects of experience that are not already present to reflective consciousness.

The pre-reflective dimension of lived experiences *only appears*, as Husserl stresses, *by contrast with the modification of consciousness which consists of directing one's view towards the lived experience itself*, and thus to 'become conscious' of it or bring it into 'reflective consciousness'. (Vermersch 2009 p.37)

It is possible to observe this modification of consciousness occurring. It involves an intuitive donation, which renews contact with the lived experience itself and often brings forward surprising information that was not always already present to reflective consciousness. Achieving the transition between the reflective natural attitude and an accessing gesture towards the pre-reflective requires learning a new attitude that Vermersch refers to as the 'phenomenological witness' (Vermersch 2009 p.37). Achieving the reflective position of the phenomenological witness involves a deliberate but effortless letting come. This is not an effortful process of reasoning.

One of the major difficulties is created by the fact that the subject makes 'efforts' to remember, while one of the technical bases is to solicit an effortless memory, a letting come. What is at stake is authenticity, clarity, and fidelity to the intuitive donation of the past lived experience. (Vermersch 2009 p.39)

Establishing the 'authenticity, clarity and fidelity' of this intuitive donation of lived experience and, consequently, of the data that are gathered in this manner requires a thorough knowledge of how this gesture operates and an ability to observe and therefore verify its presense. These issues are discussed in depth in sections 4.5, 5.5, 6.3, 7.6, and 7.6.10, and in chapter 12.

Secondly, even in the case of memory, Kahneman's peak-end rule implies that subjects would be most likely to recall recovery well. Kahneman's peak-end rule states that "... the evidence suggests that the instant utilities of the end of the episode and of its affective peak often dominate its remembered utility" (1999 p.16). Given that recovery is the end of the episode, recovered participants are very likely to be able to report it accurately. Kahneman's peak-end rule also suggests that recovered subjects will recall 'affective peaks', the worst and best aspects of their illness experience, in terms of affect. This stands to support the investigative process considerably as it appears that one of the dynamics of the being-ill state is a lack of access to affect. It is possibly the case, therefore, that ill interviewees are not able to relate the affective dimension of the illness. Given that this affective dimension is well remembered, potentially, recovered interviewees provide a source for understanding this dynamic of the illness. This not only adds to our understanding of the illness, but potentially also contributes to the formulation of a treatment programme. One disclaimer must be placed on this second point with respect to

the use of data from the recovered subjects: Kahneman's work was developed in the context of economics. The present research, is concerned with in the character of the experience of CFS, not principally its utility.

Maurel (2009) provides a revealing example in this respect: a nurse recounting an experience of learning many years after the event. This example demonstrates how the evocation position is different from that of simply remembering an event.

Even where some defective memories may be involved, arguably, this is still not good reason to abandon the possibility of research.

There are no mechanical processes to resolve this problem from the outset: the subject will never be a tape recorder or a video recorder which records everything accessible to them. The picture is bleak, and may lead to the temptation to do without what the subject says, *but in no science has one ever abandoned studying a field on the grounds that it was difficult to grasp!* (Vermersch 2009, p.53)

What is initially required is the means by which to establish the authenticity of the data.

In these different research frameworks which take into account the first person viewpoint, authenticity is the criterion which enables the attribution of information value to the descriptions produced. Authenticity is not ersatz truth, but it is the criterion which establishes the descriptive value of the verbalisations produced. (Vermersch 2009, p.54)

Establishing the authenticity of the data is a process that begins during the research interviews by monitoring the quality of the introspective act.

I have come to realise that introspection is a perceptive act, and that authenticity is primarily the apperception of the quality of the perceptive act. Even if it is a perceptive act in the past lived experience. (Vermersch 2009, p.55)

After this initial stage the authenticity of the account of the experience is further established as the structure of the experience is identified, analysed and conclusions are drawn.

The specific application of the methodology developed in chapters 5 and 6, as employed in this research, is presented in chapter 7.

7. Method

In a generative view, the other and I are a common ground, a joint tissue which is tangibly present in empathy and affect, which offer a possible level of analysis if we avail ourselves of the means to do so. (Depraz and Cosmelli 2003, p.87)

7.1 Introduction

This chapter details the specific application of the methodology developed above as employed in this research. The importance of the practice of empathy and the ways in which this practice informs the goals of the project are presented in section 7.2. Here I provide reflection on my own subjectivity and intersubjectivity with respect to the research process. This reflection endeavours to identify any instrumental effect resulting from myself as the researcher. The ways in which the intentions of the research are informed by the pilot study are discussed in section 7.3. The implications for the research process of the requirements of ethical approval are discussed in section 7.4. The process used to recruit participants for the research is described in section 7.5. The interviewing process is described in section 7.6. This section details the means by which a full categorising description and systematic evaluation of the phenomenal domain was calibrated and validated through the use of saturation and the intersubjective regulation of ‘phenomenal filling-in’. Examples of the explication interview process are provided with commentary. How validity and authenticity was achieved is described. Section 7.6.11 draws practical, theoretical and methodological considerations from the researcher’s own experience of empathetically relating to an experience of suffering. The processes required to generate transcripts of the interview material and make these available for the participants to review are reported in section 7.7. The identification of textual invariants is described in section 7.8. The processes required to model the relationships between these invariants in order to formalise the experience are described in section 7.9 and the resulting models and the contribution of these models to the formation of the analysis chapters are presented in section 7.9.1. The chapter is concluded in section 7.10 with remarks on how this method could be improved in future research.

7.2 Empathy as a Working Experience

Empathy as a working experience (Depraz and Cosmelli 2003, p.166) was of considerable importance in this research from its inception. The first academic account of CFS I considered was Showalter’s (1997, pp.115-132) explanation of CFS as a contemporary form of hysteria. This assessment raised my curiosity, less for the nature of Showalter’s account than because of the discrepancy between this account and the others I would later review (Strickland et al. 2001; Stricklin, Sewell, and Austad 1990; 1992; Abbey and Garfinkel 1991; Shahar and Lederer 1990; Brunello et al. 1999; Wessely 1997; Saltzstein et al. 1992), and my second-person awareness of

the experience of a colleague who has lived with CFS for more than two decades. Not only were the accounts of CFS provided by the academic literature often contrary to what I had witnessed, further, I was struck by the absence from this literature of any first-person phenomenological account of the experience of CFS. The majority of this literature employed a purely third-person perspective. Furthermore, the issues of concern to my colleague, based on her first-person experience of CFS, seemed very divergent from those approached by existing research. There was no evidence of a relationship of mutual constraint or reciprocity between the first and third-person despite the fact that the third-person research was clearly reliant on first-person accounts. This reliance on first-person accounts is particularly the case for a diagnosis such as CFS because CFS can only be ascertained on the basis of descriptive symptomatic accounts. There are no established biomedical tests for the condition. Perceiving my colleague's distress at their CFS experience to be worthy of concern and respect (see section 7.3), I decided to investigate the first-person experience of CFS. The goal for the research became twofold: to address the absence of first-person phenomenal data and to address this lacuna in such a manner as to facilitate a relationship of mutual constraint between the first- and third-person evidence.

With respect to clinical practice, Toombs (2001, p.254) asserts that empathy with the bodily experience of the other requires the learning and unlearning of bodily normality. An illness such as CFS lies well outside of most individuals' experience of both bodily normality and abnormality. The significant degree to which the participants report that others are not able to comprehend their experience is perhaps testament to this (see sections 8.4 and 8.9). A diagnosis of CFS is not universally accepted. It can often involve considerable stigma and frequently leads to an unusually long and unpredictable period of illness.

Although I have no first-person experience of CFS, my first-person experience of an undiagnosed illness that extended over almost a decade has provided me with a first-person perspective on chronic illness and the ways in which illness transforms the self. I consider that my illness experience enhanced my ability to empathise with the participants in this research. Illness is an experience that educates the subject in the unlearning of bodily normality. I have a first-person awareness of the implications of being unable to present an explanation for incapacity that is adequate in the eye of the other. I have had first-person experience of stigmatisation due to illness and experienced the ways in which an extended period of illness impacts upon many areas of one's life.

The only way in which to accurately assess any instrumental effect of the interviewer is to repeat the study with a different interviewer or multiple interviewers in order to assess the influence of the interviewer(s) upon the results. My first-person experience of an undiagnosed

illness gave me an ability to empathise with the interviewees, which could be considered a positive instrumental effect. The danger is that this past experience may have led me to assume that aspects of the interviewees experience were identical to my own experiences. This could lead me to inadequately progress to saturation the interview process with respect to these aspects of experience. Equally, assuming the relevance of my experience may have affected my ability to remain non-directive as an interviewer. To avoid these limiting instrumental effects, I deliberately ‘played dumb’ with respect to aspects of the illness experience that apparently concurred with my own experience. These aspects were relatively rare, given that my own experience of illness was in most respects very different to that related by the interviewees. The same approach was taken to interviewees descriptions of meditation and energy. I did not prompt discussion of meditation or energy, or inform the interviewees of my own meditative or energetic practices.

Toombs (2001 pp.254-5) cites mindfulness meditation as an example of a practice that enhances subjects’ acquaintance with their own bodily normality. This acquaintance forms the basis for the ability to imagine and empathise with the bodily experience of another. As a practitioner of the disciplines of Hatha Yoga (Coulter 2004) and Qigong (Johnson 2000), I have engaged with significant tools for developing such acquaintance. I believe that my own practice of these arts has increased both my conscious embodiment and my first-person sensorimotor awareness and consequently my empathy towards the embodied experiences of another. As a teacher of these arts, I have experience of being the second-person facilitator of the process of others becoming acquainted with their own bodily experiences. Teaching these arts creates a forum through which this form of empathy is put into practice. It provides the opportunity to develop empathic listening and the exercise of imagination with respect to the lived experience of another. As a practitioner of a Qigong form, the focus of which is the cultivation of compassion, I have, as de Waal, Thompson et al. encourage (2005, pp.43-51), actively cultivated empathy.

Cultivating the awareness of experience involves attending to its bodily donation. Gendlin argues that developing as a person requires that we develop this letting come: “our bodies carry our situations ... our bodies can total up years of all kinds of experience and at any moment give us something new, a new more intricate step” (Gendlin 1992 p.11). The practices of Hatha Yoga and Qigong are disciplines through which this bodily awareness is developed. These disciplines teach the practitioner to pay attention to the intricacy of experience by focusing on the body. The practitioner is focused on the ‘how’ of the practice rather than the ‘what’ and as such is able to access the deeper introspective levels of experience that lead to insight into intricacies of

experience that could, otherwise, go unnoticed. This is a deliberate embodied act of introspection.

The quality of this introspective act is entirely in resonance with that described by Petitmengin and Bitbol in their description of the introspective act required of the subject in an interview context.

This exploration is encouraged by a particular attentional disposition, which is both open and receptive. Unlike focused attention, which is narrow, concentrated on a particular content, this attention is panoramic, peripheral, open on a vast area. This diffuse attention is however very fine, and sensitive to the most subtle changes. ... This attentional disposition is also described as non intentional, receptive. ... very alert, awake, remains loosened, detached, receptive. It does not consist in stretching toward experience to scrutinize it, recognize it, and characterize it immediately. But in being present at the singular situation, open to anything that may arise. This disposition allows us to become aware of dimensions of experience that the stretching toward a goal usually makes imperceptible. The only thing that one can do is to adopt the required attentional disposition and let consciousness come. (Petitmengin and Bitbol 2009 p.378)

Petitmengin and Bitbol (2009) discuss how an awareness of the distinction between the ‘what’ and the ‘how’ is important to the ability of the researcher to guide a subject towards the pre-reflective. Similarly a practiced ability to enter into the introspective state above is necessary for the researcher to adequately guide others towards this state. This involves leading the subject, gently, away from scrutinizing experience or, literally, stretching towards a goal. Herein lie the most common mistakes in the practice of Hatha Yoga. It is often the job of a good teacher to lead their student towards the appropriate attitude towards their practice. In my experience, being a practitioner of Hatha Yoga and Qigong has contributed to my skill as a researcher by enhancing my ability to focus on the ‘how’ and enter into the introspective attitude. As a teacher of these disciplines I have become practiced at leading others towards these same modifications in conscious attitude. Maurel (2009) discusses accessing introspective data from athletes, showing that the explication of introspective experience provides data that can not be captured by alternative means. I have observed this to be the case as an athlete of Yoga and Qigong and in my work teaching athletes these disciplines.

An initial platform for the consideration of sensory awareness within first-person research is being developed by Hurlburt et al (2009). The authors use descriptive sampling techniques as opposed to the explication interviews used in this research. None the less this work has drawn my attention to how Yoga and Qigong have enhanced my ability to pay attention to sensory awareness, particularly touch, kinaesthesia, proprioception, the awareness of movement and movement possibilities. These disciplines promote both the flexible movement between and sustained attention to sensory awarenesses and other modes of consciousness such as, for instance, a deliberate concentration of attention on the breath. This background potentially

enhanced my ability to identify both the presence and the absence of sensory awareness in the accounts offered by the subjects of this research. Similarly it may have developed my ability to aid the subjects to maintain the focus of their attention. This is a crucial aspect to the success of an explication interview (Petitmengin 2006) and may amount to a positive instrumental effect of myself as the researcher in this case.

Similarly, the feeling point perceptual position (Andreas and Andreas 2009), may be developed by the practice of Yoga and Qigong.

These life experiences contributed to my ability, in Varela and Shear's (2000, p.10) terms, to model the internal life of the experimental participant. They facilitated my ability to determine the reference experience others with chronic illness are grasping as the target of their reflection and verbalisation (see section 5.6). These areas of 'know-how' contributed to my particular situatedness in exchange as a second-person facilitator and the empathic basis on which that situatedness operates (see section 5.6). My knowledge of the first-person experience of chronic illness allowed me to function, to an extent, as a second-person that had "been there" (Scharmer 2000, p.7). This aided in establishing my position as one of empathic resonance. I was able to find a resonant chord or a common experiential ground (see section 5.6) from which to facilitate the participants' exploration of their experience of CFS.

7.3 Pilot Study and Research Intentions

Given the substantial absence of prior work on CFS engaging the first-person perspective, I decided to employ an exploratory approach to enable me to identify as many of the narrative-time phenomenal invariants in this domain as comprehensively as possible (see section 5.2). My initial intention was to use a combination of focus groups and individual interviews to collect first-person phenomenal data (see section 5.3). I was also interested in the possibility of video taping these sessions for analysis. I wanted to capture as many elements as possible of the research participants' expression and verbal articulation of the lived experience of CFS (see section 5.6).

From the outset of the research, I was concerned to treat the participants' articulation of their experience as an explanandum in its own right (see section 5.4). For this reason, I was not concerned to gather third-person data, such as information from participants' general practitioners³⁶. Doing so does not imply that first-person data is private or that it cannot inform third-person research (Scharmer 2000, p.8). The scope of the empirical component of this

³⁶ A general practitioner is "a doctor (also known as a *family doctor* or *family practitioner*) who is the main agent of primary health care, through whom patients make first contact with health services for a new episode of illness or fresh developments of chronic diseases" (Martin 1994, p.269).

research, however, was to systematically evaluate the phenomenal data without undermining its irreducible givenness and to allow it to inform the research process in an heuristic fashion (see section 5.4). This included the choice to conduct the research using a first-person psychophenomenological methodology and to analyse the data from an enactive and neurophenomenological perspective.

Prior to commencing the research, a pilot study was conducted. Through word of mouth, I contacted three women who were either self-diagnosed with CFS or had received a diagnosis from a general practitioner. I invited each of them to participate in a single interview session which I would conduct. Using open-ended, semi-structured questions (Hart and Grace 2000), two in depth interviews were conducted in a quiet room on campus. These interviews were audio taped. I transcribed the interviews and checked the transcriptions against the audio tapes.

The third individual declined to be interviewed in person and asked instead to respond in writing. The reason she gave for this request was her view that her illness experience was a ‘very private issue’³⁷. In the past, she had experienced considerable ‘stigmatisation’ and felt ‘stereotyped’ when she had attempted to articulate her experience. She stated that she would feel more comfortable if she could respond to questions with ‘considered’ written responses. I agreed to this request and she submitted written responses to my pilot interview questions.

Prior to the interviews, the issues of privacy and stigmatisation also arose in conversation with the two participants who did agree to be interviewed. They stated that their experiences of facing stigma and stereotyping had undermined the importance they wished to place on the various aspects of their illness experience. All the participants expressed a sense of vulnerability with respect to speaking with another about their illness experience. They considered their experience to be very individual and stated that they did not necessarily adhere to the same views as other sufferers.

Placing myself in the participants’ position, I decided that group interviews or the use of video taping would not be appropriate for any initial research. It was clear that as an ‘other’ to the participants, I would need to establish individual relationships of trust and respect (see section 7.3). The outcome of this for the research was my decision to limit the collection of phenomenal data to the verbal expression of the experience of CFS offered within clearly delineated individual confidential explicitation interviews (see section 7.6). This would enable an approach to the data collection that allowed me to respect the relative importance the participants wished to place on the different aspects of their experiences, respect the participants’ need for privacy and most effectively avoid experiences of stigmatisation or stereotyping.

³⁷ In cases where I use the same word or phrase as the participants, the words are enclosed in single quotation marks.

Analysis of the pilot study transcripts also showed that capturing an individual's experience of CFS was likely to take considerably more than one interview session. Time was needed to build rapport with the participants. The complexity of the experience could not necessarily be reviewed in one ninety minute session and it would take practice and patience to achieve a sustained and rich examination of the phenomenal invariants related by each individual. Analysis of the pilot study transcripts suggested that achieving a comprehensive examination of the phenomenal invariants would require recruiting participants who had been ill for different time periods and require recruiting participants who considered themselves recovered from CFS. Recruiting participants through the ME Support Groups would enable the research to include participants' experiences of belonging to these groups. I would also need to interview women who were self-diagnosed or who, for whatever reason, chose not to see a general practitioner. Material from the pilot study suggested the value of recruiting participants through randomly selected general practitioners to understand their experience and to find participants who had not had contact with the ME Support Groups. One of the participants in the pilot study had consulted a general practitioner who had a specific interest in treating CFS. This highlighted the importance of including participants with this more specific experience. Lastly, material in the pilot interviews indicated the value of recruiting participants from different geographical areas given the regional variation in health care services.

7.4 Ethical Approval

Ethical approval for the research was granted by the Canterbury Ethics Committee, the University of Canterbury Human Ethics Committee and the Wellington Ethics Committee. The ethical requirements of the Canterbury Ethics Committee and the University of Canterbury Human Ethics Committee were consistent. The Wellington Ethics Committee required that I return copies of the interview transcripts to the participants to allow the participants to ensure that the interview material would not make them identifiable.

7.5 Recruitment Process

To recruit participants for the research, I wrote to thirty randomly selected general practitioners, and five general practitioners who had an interest in treating women with CFS in each of the two geographical regions, Canterbury and Wellington. Located on each of the main islands of New Zealand, the Canterbury and Wellington regions are the most comparable in size, population density and ethnic diversity. The letter I wrote to general practitioners (appendix C:) included a copy of my Information Sheet (appendix D:) and Consent Form (appendix E:) and five copies of an Invitation to Participate (appendix F:) for distribution to patients they felt would be suitable

for the research. I followed up this letter with a phone call to address any questions or queries the general practitioners concerned might have. The Invitation to Participate offered women who had or had recovered from CFS the opportunity to contact me to talk through any initial concerns and to receive the more detailed Information Sheet (appendix D:) and a copy of the Consent Form (appendix E:).

In Christchurch, I telephoned the Christchurch ME Support Group and arranged to attend a meeting where I talked about my research and made thirty copies of the Invitation to Participate available to any members who were interested in the research. In Wellington, I telephoned the Wellington ME Support Group and their organiser suggested that, since there were no suitable meeting times, I send copies of the Invitation to Participate to their office so that they could post it to their members. I accepted this proposal and sent thirty copies of the Invitation to Participate in thirty stamped envelopes to their office. So that the expense of contacting me would not be a barrier to participation for the Wellington participants, I used a free calling number on the Wellington Invitation to Participate.

Taking up the 'invitation to participate' in the research provided the interviewees with the opportunity to request to participate and be interviewed. This request was initiated on their behalf and involved a separate process of contacting the researcher to that involved with giving consent by signing the 'Consent Form'. This is not dissimilar to the example of Franck in Maurel's (2009) research.

When women contacted me after receiving the Invitation to Participate, either from their general practitioner or through one of the support groups, I attended to any concerns about the research. If they were interested in participating, I mailed them copies of the Information Sheet and Consent Form and arranged to follow this with a telephone call in which I addressed any further concerns. At this point, if the person wished to participate in the research I organised an initial interview time. Without exception, those interested were concerned to establish rapport with me before they were prepared to consent to participating in the research. Conveying my personal experience of chronic illness, my understanding of stigmatisation and stereotyping and my acknowledgement of the vulnerability that these experiences can create was a significant component of my ability to establish initial rapport and trust. This first-person knowledge of the experiential domain allowed me to resonate with the concerns of those who were interested in participating (see section 5.6). In the majority of cases, this process of building rapport was repeated again when the participant met me in person for the first time at the beginning of the first interview.

In those instances where more than one interview session was required, subsequent interview times were organised at the end of the previous interview. A separate consent form was used for each interview and was dated and signed at the beginning of each interview session. The Consent Form (appendix E) was used to gather participants' permissions to tape record each interview.

Due to the impact of the illness on many of the participants, I decided to offer to conduct the interviews at participants' homes. All the participants took up this offer. Thirty women participated in the research, fifteen from the Canterbury region and fifteen from the Wellington region. From each area, approximately two thirds of the participants were suffering from CFS at the time of the interviews and one third had recovered. Across both geographical groups approximately half of the participants had been involved with a support group, approximately half of the participants had come to a diagnosis themselves initially, four had been diagnosed by an alternative practitioner and one third of the participants had received an initial diagnosis from a general practitioner. Two of the participants had chosen not to seek advice from a general practitioner, approximately one third sought advice from a general practitioner who had a specific interest in treating CFS and approximately two thirds of the participants sought advice from a general practitioner who did not have a specific interest in treating CFS. Amongst these 'subgroups', approximately two thirds of the participants had sought advice from an alternative practitioner. The mean time of participation was three ninety minute interviews. The shortest time of participation was a single one hour interview and the longest time of participation was six ninety minute interviews. Appendix J presents the amount of material contributed by each interviewee to the project, and the amount of material from each interviewee quoted in the analysis chapters that follow. This excludes the extracts in the next section.

7.6 The Interviews

7.6.1 Introduction

The goal of the interviews was to gather phenomenological data through which I could capture the invariant structural features of the experience of CFS as comprehensively as possible (see section 5.2). The interviewing was designed to facilitate a systematic evaluation of this phenomenal domain through three processes of textual invariant saturation³⁸ occurring within the interview(s) with each participant, across the participant subgroups and across the interviews as a whole. These textual invariants are the symbolisations of phenomenal invariants (see section 6.3).

³⁸ Saturation has occurred when further data fails to produce any new evidence of phenomenal variability to that which has been established. See section 6.4.

7.6.2 The Initial Stage

My goal was to facilitate a thorough investigation of the textual invariants in the case of each individual participant (see sections 5.6 and 6.3). My initial interview question was very broad and invited the participant to describe their experience of CFS in their own terms. All subsequent interview questions were non-directive and structured to encourage the participant to continue to relate textual invariants in their own terms (see section 6.10).

The participants were initially inclined to mention, in a list like fashion, all the aspects of their CFS experience. In briefer cases this typically formed the first section of the first interview. In most cases, however, this initial process often took up the majority of the first interview. Vermersch comments:

But relating to a class of lived experiences, to a generality, or to a time period which is too large and exceeds the unfolding of an action, does not mean giving oneself intuitively a lived experience, but having a thought relating to this class of lived experiences. Instead of a contact, we have an overview of a generality. Without an intuitive donation it becomes impossible to access the pre-reflective content inscribed in each lived moment; without this donation the subject will produce a 'signitive' discourse about generalities, invariants common to these actions. ... This will not produce introspective information about what the informer does really when he is in action, and particularly what he does in the pre-reflective consciousness mode, which is always more than what he thinks he knows about what he does! (Vermersch 2009, p.39)

The textual invariants related in a list-like fashion by the interviewees are an example of the subject producing a 'signitive discourse about generalities'. In order to generate genuine phenomenological data it was necessary to deepen beyond these generalities. The density of coding applied to an area of transcript often reflects the level of generality of the experiences being related. Where a section of transcript records experiences with a high level of generality the coding of these passages is often much denser with codes containing small pieces of text and referring to numerous different nodes. In comparison, a transcript section of similar length where an experience is related with more depth may involve coding that refers to as little as one or two nodes.

7.6.3 Deepening the Process

To achieve a saturation of and sustained examination of the textual invariants, one that had the necessary richness, I encouraged the participant to take the actions of suspending normal mentation and redirecting or converting their attention toward each emergent phenomenal invariant (see section 5.5 and 6.3). These phenomenal invariants were always those initially described by the participant (see section 6.10). To complete this process of 'phenomenal filling-in' required the majority of the total interview time and required a process of 'intersubjective

regulation' whereby I would check my understanding of the participants' experience with them and the participants would likewise check my understanding (see sections 5.5 and 5.7).

The subject needs to be motivated to cooperate with the experimentalist and empathically to understand her motivations; and reciprocally the experimentalist needs to facilitate the subject's finding his own phenomenal invariants. Without this reciprocal, empathically grounded exchange, there is no refined first-person data to be had. (Lutz and Thompson 2003, p.40)

As the second-person researcher this required an attitude of openness towards the participants and engagement in an heuristic process in order to achieve a full categorising description of the phenomenal domain (see section 5.7). This self-othering on behalf of both participant and researcher was necessary to facilitate linguistic interpretation (see section 5.8).

The participants often initially required an opportunity to cultivate the actions of suspension and redirection (see section 5.5 and 6.3). After the participants were more familiar with the basic cycle of epoche they became more able to tolerate or accept a period of time in which there was 'nothing happening' (see section 5.5 and 6.3). This provided the grounds from which the participant was able to engage in 'letting go' and allow the 'letting come' of the objects of intuition (see section 5.5 and 6.3). As each participant became more competent with each aspect of the cycle of epoche and I became more competent as a second-person, one who was more familiar with the invariants of concern, phenomenal plasticity began to stabilize (see section 5.5 and 6.3) and a finer grained quality to the participants' verbalisation became possible (see section 5.6). As this stabilisation arose and saturation of textual invariants occurred, it became clear that the research process was demonstrating apodicticity with respect to the invariants concerned (see section 5.6).

Having all the basic components of epoche in place provided a clear procedure for accessing the phenomenal domain and establishing expression and validation (see section 5.5). Acting as a second-person facilitator for the actions of 'letting go', 'letting come' and the expression of the intuitive objects that arose from these actions required that I establish considerable rapport with the participants and a clear relationship of empathy and trust. For the participants to share their experience of 'letting go' and 'letting come', it was important that I treat the participants as persons worthy of concern and respect and that, as a second-person resonating with their experience, I demonstrate my ability to transpose, to use Thompson's (2007, forthcoming pp.582-91) term, myself into their situation. Facilitating this process also required that I learn to tolerate the 'nothing happening' that often occurred between the basic components of epoche and verbalisation (see section 5.5). This required that I acknowledge the fact that the act of expression does not necessarily occur simultaneously with the act of reflecting

on experience (see section 5.6). During the later stages of the interview process I reported back to the participant my understanding of what they were communicating and asked them to confirm my understanding (see section 5.6). Applying the ‘basic attitude’ and following it with a verbal expression, mediated in this way, provided a means whereby the phenomenal data could be intersubjectively validated, shared and calibrated to a fine grained quality (see sections 5.5 and 5.6). It also further confirmed that phenomenal plasticity had stabilized (see section 5.5).

7.6.4 Inter-session Review

To ensure that I had identified all the textual invariants that each participant mentioned, I reviewed the tape recording of each interview before any subsequent interviews, noting down any partially explored invariants, including invariants that emerged from across more than one interview. This provided the means for an intra-individual (Depraz and Cosmelli 2003, pp.192-4) comparison of participant performance (see section 5.7 and 6.4). When this process was complete, I reviewed the list of topics (derived from the pilot study transcripts) that formed the basis of the two interview schedules I used for all the interviews. One interview schedule was designed for participants that were ill at the time of the interviews (appendix A) and the other for participants who had recovered (appendix B:). If a topic area had not been volunteered by the participant, I raised the topic as part of the final section of the interview process. Lastly, I encouraged the participant to consider whether there were any aspects of their experience of CFS that they had not mentioned. When the participant was able to confidently answer that there were no further aspects to their experience, the final interview was brought to a close.

7.6.5 Inter-individual Validation

The second means by which I ensured I was capturing the textual invariants as comprehensively as possible was through a process of inter-individual (Depraz, Varela, and Vermersch 2003, pp.94-5) validation. I recruited and interviewed participants from each of the subgroups until I was satisfied that I had identified the full spectrum of textual invariants within each subgroup. Rather than view inter-individual variability as irrelevant or contradictory, I explored these differences. In the majority of cases, this process led to identifying new textual invariants, refining the grain of the invariants identified and deepening the validation achieved (see section 5.6). This process also allowed me to identify whether an invariant was relevant to the phenomenal domain under investigation.

Lastly, the same process of textual invariant saturation was established across all the interviews. Interviews were conducted with three participants beyond the point at which I was confident that saturation of each subgroup and saturation across the interviews as a whole had

been accomplished. No new textual invariants arose during the interviews with these final three participants. I consider that the two processes of saturation, inter-session review and inter-individual validation, provided a clear procedure for the assessment of the phenomenal domain (see sections 6.3, 6.4 and 6.10).

7.6.6 The Explicitation Interview Technique

The use of the explicitation interview is being developed in a number of settings including: research in the science of consciousness, education, therapy and the understanding of specific aspects of experience, such as intuition (Petitmengin 2006, 2009; Petitmengin-Peugeot 1999).

Based on Vermersch's psycho-phenomenological investigation of the act of introspection (Vermersch 2009), the explicitation interview (Maurel 2009) involves the researcher taking up the second-person position and using a number of techniques to enable and teach the research subject to engage in retrospective introspection on experience. Gallagher and Varela (2003) describe the natural attitude. To achieve retrospective introspection, the subject must transition from the natural attitude to the evocation position: a position from which the subject can achieve a specific relationship with the past experience under investigation and allow for 'intuitive filling-in'. This relationship allows the subject to acquire reflective consciousness of their previously pre-reflective subjective experience: "it is a matter of being present in relation to his lived experience as a lived experience, and not of thinking about his lived experience, which is something quite different" (Maurel 2009 p.60).

The excerpts below demonstrate various aspects of this technique. Excerpt 1 involves material taken from two consecutive interviews with an interviewee who was from the Wellington region of New Zealand and who was ill at the time of the interviews. Excerpt 2 involves material taken from three consecutive interviews with a research subject from the Canterbury region of New Zealand who had recovered from CFS. The subjective experience that is accessed through the explicitation interview cannot be obtained through third-person techniques (Maurel 2009). This difference is what makes the data derived from such investigation relatively unique.

7.6.7 Excerpt One

Interviewee A Interview 1

1. BH: The pain. What was the pain like?

2. I: Um ... the pain, just aches and pains, I guess. [long pause] Except once ... in one of my efforts to ... I have really bad back pain. This has always been a feature of my ME. Up the spine. I think that must be something to do with where the nerve ends are or something. I got out the book: "Look After Your Back" and so I did these back exercises one day and the following day I couldn't move. *I ... couldn't ... move* [strong emphasis]. I could hardly walk. To go to the toilet [long pause] my husband had to kind of help me, and I just remember lying flat all day. What I realise now, was that, it was a total build-up of lactic acid in the muscles, but then I didn't know what'd happened. All I knew was that I'd done these back exercises and the next day I was a mess.

3. BH: What was the pain like?

4. I: Well I don't know that I can add any more ... it was sort've, pain in my joints, pain in my back, ongoing, and when I did exercise it got worse, yeah?

5. BH: Okay. What's it like ... for the joints? [pause] Is it shooting pains, is it aching pains, is it?

6. I: Oh right. It's aching ... it's aching pain. [long pause] It's, aching ... and it's ongoing.

7. BH: mhm [affirming]

8 I: [pause] And it takes, it takes a long, well, it takes longer to go, than it normally would if you were healthy. Like, I did a bit of practice of the old Latin American dancing three days ago, only five, ten minutes, and, it hurt, today it hurts, yesterday it hurt. I'm having trouble walking today. That's three days. It'll probably take me another three, before it's gone, whereas normally, you're over that sort of stiffness a lot quicker, yeah?

9. BH: okay, so it aches and it's ongoing. What is the ache like?

10. I: It's aching [pause] and it's ongoing. Yeah?

11. BH: Mhm. [pause] Okay. How does the aching feel?

12. I: Oh right. [long pause] It feels like ... the muscles ... are aching. Like ... the strings inside them ... are tight ... and weak.

13. BH: The strings are tight ... and weak.

14. I: aching ... and tight [long pause] and weak.

15. BH: [pause] anything else?

16. [pause] No ... just aching and ongoing.

17. BH: [pause] Any other sort of pain?

18. I: [pause] I don't get stomach pain anymore. ... I used to have stomach cramps at the beginning ... a bit ... I think ... but I don't get that. Yes ... joint pain, back pain, it's muscular really, it's not joint, it's muscular. I mean it's in the ... yes, I can feel it now in my legs and in my arms [touching legs and arms] it's, yeah, there is definitely muscular pain there as well.

19. BH: Is it in the joints, or the muscles, or both?

20. I: It's ... muscular.

21. BH: Not both?

22: No. It's muscular.

23. Mhm, mhm. What's it like for the muscles [gesturing to legs and arms]?

24. [sighs slowly] It's the same thing ... it's an ache ... it's an ongoing ache. [long pause] One thing I do notice though, is that if I get up and potter around ... it actually frees it up a little bit ... so it, sometimes, helps, a bit.

25. BH: Mhm ... yeah ... mhm

26. I: So but again ... it's-it's-it's-it's, it's constant it ... it-it's not shooting pains ... it's not just there sometimes ... and not others I mean ... and I find, the pain ... also ... um ... like I find if I have a long trip in a car or in a plane, ... that ... even if I haven't done lots of exercise before ... even if I've rested up well before the journey, I find that ... being stuck with it ... in one position ... really seems to make it a lot worse too ... you're not being able to move around a bit.

Interviewee A: Interview 2:

27. BH: Coming back to the pain, you were talking about the back pain, anywhere else?

28. I: Yeah ... definitely ... it's difficult to describe, because again at different stages it depends what you've done. If I spent a week, just lying around, I could probably be ... reasonably ... pain-free ... but, I can't stand doing that.

29. BH: What you've done ...

30. I: I mean, I don't do much physical activity ... I walk [pause] I garden. So the pain depends ... on the level of activity with me ... really ... as I say, I think if I lay ... supine ... for a week ... I would be pain-free. But, [long pause] I get ... really weird pain, like ... it is joint, definitely joint pain, hips, elbows, um, shoulders and the back. The back is worse, always the constant one in the back. As I say I think, from what I've read it's sort of the build-up of lactic acid after activity. The other odd thing I get which sounds really mad, is I get really hot hands and feet.

30. BH: Mhm, hot hands and feet

31: I: Hot palms, hot soles of my feet and ... somebody who had arthritis said, that that was quite an arthritic thing, that sometimes happens with people with one of the kinds of arthritis. I can't remember which kind ... and if I'm over-tired, that gets really bad, and it's really uncomfortable it's not so much painful.

32. BH: Mhm

33. I: But it's very uncomfortable ... it's difficult to sort of sleep with it ... so that's what the pain's like.

34. BH: Okay, hot

35. I: every night, I mean I have quite a lot of pain every night. I take painkillers ... um ... because I can't sleep unless I do. They're only panadol ... I don't, take painkillers in the day ... um ... because I don't want to.

36. BH: This hot pain, is it joint ... or muscular?

37. I: joint [pause] not muscular.

38. BH: so the joint pain ... is hot [pause] and the muscular pain ... is aching?

39. I: yes, hot ... like burning ... but not like burning muscles.

40. BH: burning

41. I: [sighs] Yeah

42. BH: Yeah, What is the burning like?

43. I: burning ... from ... the inside [looking uncomfortable]

7.6.8 Excerpt Two

Interviewee B

Interview 1

1. BH: What was the pain actually like, how did you experience it?

2. I: Oh, there were all different sorts. I got some headaches.

3. BH: mhm, mhm [affirming tone]

4. I: dull throbbing headaches, yip

5. BH: yip

6. I: I ... had the stomach cramps with diarrhoea

7. BH: yip

8. I: the burning muscle fatigue ... and I think that's a combination of feeling like your muscles had been over-stretched and that they had acid in them

9. BH: mhm

10. I: joint pain, aching bones, sort've rheumatically pains [pause], yeah. I think that covers it.

Interviewee B: Interview 2

11. BH: You mentioned muscular tiredness. Can you describe that for me?

12. I: ech, and joint pain. It feels like ... you've done, about twenty times, what you've done, and your muscle's are stretched, and tired, and aching. You know, that acid burn ... that you get, when you've done a lot ... an awful lot of exercise.

13. BH: mhm

14. I: Um, I've read research, I don't know, if you've come across it, that people with ME, for some reason, there's some malfunction, and their muscles produce, seven times as much lactic acid for every movement ... than a normal person's does.

15. BH: mhm

16. And that accounts for that, to a large degree. Muscles also don't get rid of waste products, I'm told. That's what I had explained to me, and in terms of my experience, it makes very good sense.

17. BH: mhm

18. I: There's a burn. There's a feeling of being stretched, and tired, and there's a ... general dull ache.

19. BH: aha

20. I: Not, not a nice feeling.

Method

21. BH: no

22. I: Yeah.

23. BH: Your saying a burn, um, a general dull ache

24. I: mhm

25. BH: ah ... are they both around all the time, or?

26. I: Well ... when do you mean? When I'm flat now, or when I was ill?

27. BH: When you were ill.

28. I: When I was ill [pause] basically ... constantly

29. BH: right

30. I: yeah

31. BH: And, after that?

32. I: Um ... hardly ever. I'd say, things still aren't as effortless, as they were before I was sick. It's a hard one ... to come back from. But, um, hardly ever now

Interviewee B: Later in Interview 2

33. BH: Last time you talked about muscular tiredness

34. I: mhm

35. BH: How are your muscles now?

36. I: Almost completely better.

37. BH: yeah?

38. I: Just, I'm probably slightly more, slightly ... fractionally ... more prone to getting muscle fatigue, than, you know, a person who hasn't had ME.

39. BH: Right. How did that change?

40. I: [long pause] Very gradually

41. BH: yeah? Very gradually

42. I: Yeah, I ... it ... coming back from this thing is such a gradual process. It really does take a long time, um ... and it [muscle pain] probably it was also one of the slower things to change ... that and the memory and motor thing ... sort of the two ... slowest things to get better. The digestion picked up first I think.

43. BH: right

44. I: And then the rest followed.

45. BH: mhm, mhm ... Ah, how did that change?

46. I: Just ... gradually I felt [long pause] I seemed to feel more motivated to do things than before.

47. BH: mhm

48. I: [long pause] I felt better doing them ... um, so I'm sure it's chemical, it's something to do with the chemicals your brain releases. ... I knew I could do it ... and then gradually ... became able to do it.

49. BH: mhm

50. I know it makes it all sound very psychosomatic, but I'm absolutely positive that it's to do with chemicals in your brain.

Interviewee B: Interview 3

51. BH: Okay. Can you describe it a bit more? For what it was like for you?

52. I: achy rheumatically bones is like ... cold and dull ache is the best way to describe it ... almost like there's a chill involved of some sort ... you know what rheumatism feels like ... that sort've cold aching, sensation

53. BH: aha

54. I: and then how you feel when your joints are out of place

55. BH: mhm mhm

56. I: like very painful and bunched up or stretched out,

57. BH: yip, yeah,

58. I: usually in the same ... the two sensations in the same locus, ... yeah ... like that [long pause close to tears].

59. BH: At one point on the tape, you also said that your hands were agonisingly painful. I wondered what that was like?

60. I: I'm trying to remember the context of that [long pause] sore knuckles ... very um ... joint pain ... and sore ... yip ... fingers with muscular pain ... I suppose that was what I was talking about. So it wasn't like that that was a, a main symptom? Probably my hips were sorer than my hands ever were

61. BH: right

62. I: pelvic pain. It's still not, um, really ideal, and I think part of that's this bed has to go, it doesn't help. But, um, yeah, ... that was probably worse ... the joint pain ... and muscle ... pain in my lower back and pelvis.

63. BH: mhm ... mhm ... joint pain

64. I: Yeah, but my ... my hands, um, probably [long pause] [then with certainty] it made it harder for me to do things

65. BH: mm [pause] harder?

66. I: like ... now that I ... you've prompted me [looking surprised] ... I can remember having difficulty ... holding cups and things ... because [long pause] it was uncomfortable to clench. That ... that ... must have been fairly annoying.

67. BH: mhm, [pause] mhm, uncomfortable

68. I: Tying shoelaces [pause] was difficult. ... My hands felt [long pause] like they were burning.

69. BH: Burning?

70. I: [long pause] Hot.

71. BH: mhm [pause] how did the hot feel?

72. I: In the knuckles [pause] and on my palms ... [close to tears]

7.6.9 Interview Technique

CFS sufferers perceive a lack of comprehension of their illness by others and report numerous difficulties in their relationships with family, friends, colleagues and professionals as a result. Given this context and the stigma surrounding the CFS diagnosis, establishing and maintaining trust with the research subjects by demonstrating that they were heard, understood and respected was essential. The interviewees were willing to place trust in the research process, the process of the interviews and in myself as the researcher. This entailed being open to a demonstrative vulnerability: an openness to sharing aspects of their experience, some of which was new even to them, in a broader context where this experience has often not been respected. The research subjects did respond willingly to firm guidance and accepted my directives throughout the interviews, they expressed gratitude for the opportunity to participate in the research and a sense of satisfaction derived from participating in the interviews and offering a contribution to the research. In my experience, however, interrupting the interviewees' accounts was invariably received as a refusal to listen and a lack of respect. For this reason I used interruption only when absolutely necessary.

This needs to be seen in context. Simply participating in the research asked considerable effort of many of the subjects, some were very unwell (a number were interviewed whilst in bed) and others were experiencing considerable difficulties in communication. In this research context it was more appropriate to allow a subject to complete their report of an aspect of their experience, particularly where making such a report involved considerable effort, and then to return to aspects of that report for further explication, rather than to interrupt such a report in process. Means by which I endeavoured to assure the subjects' knew they were being listened to included paying close attention to the level of affirmation each subject required and using phrases such as "yeah", "yip" and "mhm" combined with an affirming tone of voice. Where a subject tended to interpret repetition or giving back as condescending these phrases were often a more effective means of maintaining a trusting relationship. Making clear from the outset of the interviews with each participant that I was prepared to take the time to interview them more than once also helped to establish trust. Participants did not feel pressured by any sense that they had to get it all done and all right first time, instead, they were able to relax and proceed at their own pace.

Interviews were not video taped for reasons explained in section 7.3. Consequently video taped evidence of the evocation position is not available. I paid close attention to the verbal and non-verbal cues that are associated with the embodied speech position that is necessary to ensure evocation. In my observation, when the subjects were engaged in retrospective introspection

their speech slowed and took on a rhythm that was more in tune with their breath, their choice of words was more deliberately reflective and related to their felt sense of the reported experience, gesture was often used as an extension of this felt expression. The use of 'I' and speech in the present tense was a strong indicator of most subjects being in contact with their experience. In a small number of cases, where deeply pre-reflexive aspects of experience were being reported some subjects dropped reference to 'I' and spoke in the present tense of the dimensions of experience alone. For all subjects the eyes became unfocused and eye contact was diverted rather than direct. Some subjects adopted a specific posture that seemed to accompany the act of reflection and this posture included a characteristic direction for the eyes. Often this posture involved a specific angle of the head and the shoulders.

To endeavour to demonstrate the variety of rhythm and pace in the interviewees' accounts I have used the following devices in the Excerpts One and Two. A comma indicates a pause of relatively normal length in standard communication. Longer pauses are indicated with '...' and extended pauses are marked [pause]. In general, these excerpts show how the subject's rhythm and pace changes in response to the researchers increasingly more specific prompts. The evocation position is being held for longer periods of time as the account of the experience is deepened in specificity. Examples of this change in pace from Excerpt One span lines 10-16 and 35-43 and lines 64-72 in Excerpt Two. Similarly, in these passages, I mimic the same pace and rhythm as the subject, pausing and slowing the pace of my interactions with the subject. I allow the space for the subject to pause without interruption. Where appropriate I adopted the same gestures, postures, and phrases as the subjects and this enhanced the relationship of connection.

To encourage the subject to remain in the evocation position the researcher must avoid asking questions that relate to the causality of their experience. Explaining experience enlists reasoning about experience and this is an act that is incompatible with reflecting on experience (Vermersch 2009). These are most often "why" questions. In the excerpts below, Interviewee B spontaneously begins to offer causal explanations for their experience on lines: 14 and 16. Subsequent lines show how the researcher (BH), signals to the interviewee that their comment has been heard, then does not pursue further exploration of their explanation but rather leads the subject towards the experience being explored: the pain itself.

These passages represent small sections from several interviews. The purpose of the interview process at these moments, amongst others, was to explore two specific aspects of the subject's experience: aching pain and joint pain. The relevant text from each of these passages, therefore, was coded into the relevant node: aching or joint pain. Where both forms of pain are mentioned the material is coded into both nodes. Other aspects of the CFS experience, such as

the pain involved with headaches, diarrhoea, and other digestive issues, difficulties with sleep, activity and exercise, memory and motor deficiencies, relationship difficulties, information about the recovery process and narrative concerning how the subjects make sense of the illness are also present. Consequently these passages were coded, not only to the nodes concerning aching and joint pain but also to the nodes concerned with the issues listed above. This is what inclusive, rather than exclusive coding refers to. Coding the data inclusively ensures that all the information on a particular aspect of experience is available, from the relevant node, for analysis. Using NVivo it is also possible to view the coded material in place in the original interview transcript rather than just within the node it has been coded to. As the researcher proceeds through the coding process, inclusive coding makes obvious which nodes often share the same interview transcript material and this begin to highlight the relationships between the nodes.

Almost without exception subjects began relating their experience in very general terms. These general representations often reoccurred when each new aspect of the CFS experience was initially broached. Line 2 of Excerpt One provides an example of such a general representation: ‘the pain, just aches and pains, I guess’. Beyond that the pain occurs, this singular statement provides no detail of the experience itself. General representations were also offered in a list like fashion. Lines 2-10 of Excerpt Two provide an example of this tendency to list aspects of experience. General representations such as these do not demonstrate retrospective introspection. Generalisation is just one example of a cognitive activity that is incompatible with introspective retrospection. To attain introspective data of the experience itself subjects were encouraged to focus on a singular aspect of the experience. In the Excerpts below, aching pain and joint pain are the singular aspects of experience being explored. Where appropriate, specific occurrences, such as consulting a health practitioner, or significant moments, such as receiving a diagnosis, were explored. Stages in the CFS experience were also examined. Specific occurrences, moments or stages of the experience were only explored if the subject initially offered them. This approach was taken so as to avoid engaging the subject in constructing causal explanations of their experience or aspects of the experience that were not genuine.

Throughout the interviews the subjects were encouraged to describe their experience in their own words regardless of how adequate those words may have initially seemed. I ‘gave back’ the terms and phrases that the interviewees had chosen, used their vocabulary in subsequent questions and summarised in the subjects’ terms what had been communicated. I encouraged the subjects to check whether what I offered accurately resonated with their experience, allowing them the opportunity to clarify and deepen this resonance within themselves and with me.

In the explication interview the researcher is required to use open, non-inductive prompts that are, none the less, perlocutory, precisely focusing the subject on the moment of experience being explicated (Maurel 2009; Vermersch 2009). Examples of such specific prompts returning the subject to the experience and deepening their awareness of the experience can be found throughout these excerpts. These prompts guide the subject back to their experience and request more specificity from their description.

Successfully conducting explication interviews on CFS required establishing the stability and specificity of the research subjects' attention. The stability of the subjects' attention was established through the context for the interviews in a number of ways. Interviewees recontracted their consent (Maurel 2009) to explicate their experiences by signing a consent form at the beginning of every interview. All the interviewees were given the choice of specifying the interview situation (Maurel 2009) and in all cases they chose locations that suited their needs. I travelled to the location chosen by the interviewee for every interview. The fact that the interviews were recorded also reinforced the parameters of the interview context. The tape recorder was set up at the beginning of each interview, I asked the interviewees permission to begin the recording and discussed with them the point at which the interview time period and recording would end in each session. Prior to starting the recording the subject and myself would take a quiet moment to 'focus' our attention on the interview process. This 'focusing' moment was repeated if, for any reason, the interview process was interrupted.

Specificity can also be encouraged through the use of prompts that guide the subjects' focus towards a singular experience (Vermersch 2009). Alternatively, if the goal is to address an absence in the subjects' account or provide the space in which new aspects of experience can be related prompts that are empty of information, 'empty focusing' can be used (Vermersch 2009). A question such as "what was it like before" is an example. The exploratory nature of this research required that the continuous movement back and forth between 'empty focusing' and 'focusing on a singular experience' be kept in balance. Subjects often began the interview process by relating their experience of CFS in general terms. From my perspective, initial interviews with each subject involved a mixture of sifting through these general comments for aspects of the experience and using 'empty focusing' prompts with the goal of capturing any other aspects of the subjects' experience. Later interviews involved less empty focusing and more focusing on singular experiences. Regardless of this general pattern, surprises continued to appear even towards the end of final interviews and my final question: "is there anything else you would like to mention about your experience of CFS" remained an 'empty focusing' prompt.

As the interviewees related their experience in general terms less, the length of their report tended to increase. Coded sections of interview transcript tended to increase in size as a consequence. To an extent, therefore, the coding patterns in the interview transcripts reflect the level of contact the interviewee attained with their experience. The longer the coded section of transcript and the more time elapsed (represented by pauses) the more contact with the experience the interviewee is demonstrating.

Specificity can be encouraged by ‘giving back’ what the subject has offered through the use of both verbal and non-verbal prompts, such as gestures (Maurel 2009). Lines 18-24 of Excerpt One provide examples of giving back through the use of non-verbal prompts. In Excerpt One, lines 13, 30 and 40 and in Excerpt Two lines 41, 63, 67, and 69 give examples of ‘giving back’ using verbal prompts. As Petitmiengin (2006) comments, this process of directing the subjects attention back towards the experience concerned often requires considerable determination on the researcher’s part. This required the repetition of questions rephrased, giving back of direct references, that is, pointers and handles. This can be seen on Lines 1-14 of Excerpt One. Some subjects interpreted using verbal prompts to ‘give back’ as condescending repetition. As a consequence, this technique needed to be used very carefully.

Giving back, or reformulation, was also used to check the accuracy of the subject’s accounts. Similarly, questions that required the subject to reflect on the report already provided or the specific aspect of the experience being reported were used to check the accuracy of accounts. This process was repeated across interviews where any ambiguity remained at the end of an interview session. Lines 19-22 and 36-39 of Excerpt One provide a brief example of this clarificatory process.

Focusing the subject’s evocation of their experience to an appropriate level of depth and precision for the dimension of experience under consideration was of paramount importance to the research. This enabled the subject to make present aspects of experience that would otherwise have remained pre-reflexive. Equally, in some of the subjects’ accounts, this process uncovered significant absences in their reports of the experience that seemed to persist, even with evocation. The significance of these absences became clearer through both the formalisation of the experience and the analysis process later applied to the interview transcripts.

For the subject, the process of becoming aware, in the context of the explicitation interview, often uncovers aspects of experience that the subject had not previously accessed or did not realise they were able to access. This experience is often accompanied by surprise (Vermersch 2009). Lines 2-6 and 28-32 of Excerpt One provide examples of the research subject relating more of their experience than they believed to be possible within a single interview

session. In Excerpt Two, Line 10, and the following lines from a later interview, shows this process unfolding across two separate interview sessions. Line 66 demonstrates surprise.

By exploring to an appropriate level of depth and precision the emotional, sensory and proprioceptive dimensions of the CFS experience, significant absences in the ill interviewees discourse on these aspects of experience were identified. These absences highlight important differences between the ill and recovered interviewees. The recovered interviewees' ability to make present to attention emotional, sensory and proprioceptive aspects of experience in their reports and the absence of these dimensions to experience in the ill interviewees' accounts is assessed in the analysis and discussion chapters.

Increasing the accuracy and detail in the unfolding of aspects of the CFS experience was made possible through repeated retrospective introspection. Interviewing each subject multiple times, and, therefore, enlisting an iterative process, made the revisiting of the relevant aspects of experience possible. An example of this unfolding process in the case of joint pain is demonstrated in Excerpt One. Interviewing the subject multiple times and revisiting this aspect of the experience established greater authenticity in the subjects' account and allowed the subject to correct earlier inaccuracies in their account. When this excerpt is considered alongside Excerpt Two it becomes possible to further assess the authenticity and relevance to the phenomenology of CFS of both accounts of joint pain, through inter-subjective comparison.

The interviewees were not required to establish evocation without the researchers' assistance. With practice, however, the interviewees' developed the ability to achieve evocation consistently. It appeared to be a process that had its own rewards for the interviewees. Interviewing each subject multiple times made it possible for interviewees to develop this skill. As the interviewees developed the ability to hold evocation with greater stability and intensely it became possible to access deeper pre-reflexive aspects of the experience. These aspects of the experience would simply not have been available without an iterative interview process.

My meta-knowledge (Petitmengin 2006) of the experiential categories of the CFS experience evolved within the process of completing multiple interviews with an individual subject, across the interviews with numerous subjects from each of the subgroups the research addressed and through the process of analysing the interview data. This has enhanced my knowledge of the structure of the CFS experience generally. As Petitmengin (2006) suggests, the meta-knowledge gained through the experience of conducting research on experience provides the researcher with a deepened sensitivity to the experience concerned. This did indeed require that I remain open to the surprising and continually flexible in my assessment of the experience.

7.6.10 Validity

The explication interview has been met by a number of objections concerning the validity of the process and the verifiability of the data it produces. Concerning the validity of the process, these objections have been thoroughly assessed and responded to. Equally solutions have been proposed to concerns surrounding the verifiability of data (Vermersch 1999; Vermersch 2009; Petitmengin 2006; Petitmengin and Bitbol 2009). Issues of relevance to this research include: (a) ensuring that the research subject's attention is not dispersed by ensuring that it is correctly directed (b) ensuring that absorption in the objective results of experience is avoided such that the subjective experience itself is attended to (c) ensuring that the representation of experience is not mistaken for its accurate report, (d) ensuring that the correct degree and precision and depth of experiential observation and verbalisation is achieved for each aspect of experience explored (e) ensuring that the research subjects are provided with the opportunity to best use the vocabulary available to them in describing their experience and (f) providing an interview process for each interviewee and across all the research subjects that allows for adequate opportunities for retrospective introspection to take place to adequately capture the CFS experience.

Interviews in this research were conducted such that the participants attention was stabilised, carefully directed, and taken to an appropriate level of precision and depth on specific aspects of the CFS experience, correct cognitive activity was maintained to avoid generalisations and ensure evocation was occurring where possible. Close attention was paid to the verbal and non-verbal cues that are associated with the embodied speech position that is necessary to ensure evocation. Prompts were used precisely and non-inductively. "Why" questions, and other interjections that lead to causal explanations were avoided when experience was being addressed. Subjects were encouraged to express their experience in their own terms and adequate time and opportunity was provided to allow subjects to develop a vocabulary to do so. A trusting relationship was established between the researcher and the participants such that the openness that becoming aware requires was possible. The interviews were recorded and transcribed to provide opportunities to establish compliance with these techniques and requirements. All of these aspects of the interviews contribute towards ensuring the authentic validity of the data.

The research involved several iterative processes to ensure internal reproduction of enough of the data that validity could be tested. Aspects of the CFS experience were considered multiple times within an interview session, multiple interviews were conducted with individual subjects and multiple subjects were recruited for each of the subgroups the research considered. These iterative processes ensured that adequate opportunities for retrospective introspection occurred

for each research subject and that an adequate number of reports of the experience became available from across the subjects in each research subgroup to establish intersubjective comparison and to assess the reproducibility of the experience. Future research could further confirm the intersubjective validity of the research findings.

I have not suffered from CFS and have not chosen to develop this personal expertise in the experience. The validity of the data cannot, therefore, be confirmed through an expert self-explicitation on the experience. Similarly it would not be appropriate to attempt to teach this experience to another in order to confirm the research findings. Studying whether those who have recovered from CFS agree with the findings of the research may offer a source of support for these findings. An effective treatment program based on the research may verify the research pragmatically.

7.6.11 Relating to Suffering as a Researcher

Listening closely to another's experience of suffering requires entering into relationship with that experience: one of suffering. In reflecting on my experience of witnessing the research subjects I initially noticed a strong temptation to resist entering into this relationship. Such resistance could undermine the necessary relationship of trust with the research participants. During pilot-study interviews, this resistance expressed as the temptation to become impatient: with the research subject's ability to relate their experience, the content of what was related and the amount of repetition the subjects required in order to relate their experience to their satisfaction. Initially interviews left me with a sense of exhaustion and dissociation, physically, emotionally and mentally, that could not be explained by the expected workload of conducting an intense interview. Health professionals, caregivers, and others who are involved with people with CFS have reported these same issues to me anectdotally.

As my meta-knowledge of the CFS experience increased this resistance reduced but I did not find that this was enough to overcome the resistance entirely. Instead, routinely prior to, during and after interview sessions, I used Tonglen³⁹, mindful awareness, yoga and Qigong to prepare for and attend to my experience of the participants and the subject matter of the research. The gentle movements involved with restorative yoga and Qigong seemed particularly helpful in avoiding or resolving any sense of dissociation or exhaustion. Mindful awareness and Tonglen were key to overcoming any sense of resistance or impatience. Simply appreciating that I had skills at hand that I could use to attend to my experience also helped to reduce any sense of resistance.

³⁹ Tonglen is a meditation process whereby the practitioner transforms their observation or personal experience of suffering into one of compassion (Petitmengin and Bitbol 2009; Chödrön 2001; Kamalashila 1996; The Dalai Lama 1999).

Subsequent periods of data analysis require the use of V2 and V3 on the recorded versions of the same material. To a lesser extent, this work would have a similar effect to the initial interviews, and enlisting the same strategies was successful. These observations speak to the necessity to attend to the health of the researcher when using explication interviews and introspective practices with research topics and research subjects that may have an adverse effect on the researcher. Such considerations need to be taken into account in the design of future research and treatment programs, particularly as they relate to the care of the staff involved.

This issue is not simply of practical import. It is of theoretical and methodological significance. In ideal circumstances, the researcher develops their own introspective expertise of the experience under consideration. This makes available expert self-explicitation as an important resource: “self-explicitation is invaluable in that it can combine in the same subject an expert informer and an expert analyst, while in the second-person it would be necessary to find again the informer and question him again” (Vermersch 2009, p.47). This self-explicitation becomes a source of data for revealing the structure of the experience. It is also an important means by which the researcher can establish the validity of the reports offered by research subjects.

Becoming such an expert introspective informer entails having the experience. Where suffering, illness, or other forms of pathological experience are the topic of the research this may not be advisable. Equally, subjects of such research are unlikely to be equipped to develop the “generic competence specific to mastering the explication instrument” (Vermersch 2009, p.48), that is, the expertise of a researcher, in the interests of becoming expert informers. How do we understand methodologically and theoretically the necessarily permeable boundary that needs to occur between the researcher and the experience researched in cases such as this? It is necessary for the researcher to remain open enough to the experience to be cognisant of the new, the foreign and the surprising and open to subjects in order to maintain empathy and trust. Equally the researcher needs to remain safe and well. How might this permeable boundary be operated most effectively? Are there direct substitutes for expert self-explicitation, means by which the validity of data can be established differently, in these contexts? This is a different case to an experience that involves considerable expertise as such specialised competence could, plausibly, be developed by the researcher.

7.7 Interview Data Transcription and Participant Review

After all the interviews were completed, I began their transcription. It became clear that the volume of data was greater than was reasonable for one person to transcribe in the time

available. I decided to train two typists to make initial transcriptions of the material. I wrote to all the participants requesting their permission to have their interviews initially transcribed by a transcriber of my choice, explaining that this individual would be bound by a confidentiality agreement and would not know the participants' identity. I transcribed the interviews of the participants who did not permit this option and any interviews I considered contained material that might make the participant easily identifiable. The interviews were transcribed in sequence, all first interviews being transcribed first, second interviews second and so on. Regardless of the transcriber in each case, after each interview was transcribed I checked the transcript against the interview tape to ensure that the transcripts accurately reflected the contents of the taped interviews. Any material that would make the participant identifiable, such as the names of people, places or unusual occupations was removed and a code substituted.

As with the interview process, phenomenal invariants emerged during the process of checking the transcripts. I decided to use this opportunity to begin to collate a file of significant passages from the interviews. These passages seemed to exemplify a phenomenal invariant. My choice of passages was based on my experience of conducting all of the interviews and transcribing many of them as well as reflecting on the transcripts as I checked them against the recordings. I refer to this file as the 'file of collated passages'.

Attaining ethical approval for the research from the Wellington Ethics Committee required that I make the interview transcripts available to the participants for the purpose of editing these transcripts to ensure that the material would not make them identifiable. Each participant was offered the opportunity to review their transcripts. All the participants, except one, chose to receive copies of all of their interview transcripts and all of these transcripts were returned. The participant who did not wish to receive her interview transcripts explained that she did not consider her interviews contained any material from which she could be identified. She was not concerned by the possibility that some of the interview material might be published and she was not concerned about being identified. Transcripts were mailed to the participants in the order in which the interviews had been conducted and as I completed the process of checking the transcripts against the tapes. I followed this up approximately a week from mailing with a telephone call to ensure that the transcript had been received and to attend to any questions. Very few changes were requested and very few passages were marked as inappropriate for publication. In one case, a participant had been the only New Zealand woman to participate in a particular activity and in another case one of very few individuals in a particular profession. Transcripts were edited accordingly.

7.8 Identifying ‘Textual Invariants’

Once all the interview data was available, I chose the interviews from two participants that appeared to exemplify the phenomenal invariants arising throughout the interviews as a whole. One of these participants was ill at the time of the interviews and the other considered herself to have recovered. Both these participants had participated in three one and a half hour interviews. I conducted an initial analysis on these six interviews and developed an initial list of textual invariants, apparently representing phenomenal invariants (see sections 5.2, 5.7 and 6.9). This list was then combined with any other invariants that were represented in the ‘file of collated passages’. This consolidated list of textual invariants provided me with a platform from which I began the data coding process. In this research I coded the data and established the strength and kind of semiotic relationship that existed between the invariants manually. Tagarelli and Karypis (2008) give an example of how the coding and semiotic relationship graphing process may be automated.

The interviews from each participant were imported into a designated NVivo⁴⁰ case node. Each case node was reviewed and I inclusively coded representative sections of text into nodes that were labelled according to the textual invariant that their material expressed. Inclusive coding involved coding sections of text into multiple textual invariant nodes where a section of text expressed more than one textual invariant. All sections of text expressing an invariant were coded in this manner. Sections of text ranged from a few words to several pages or in some cases substantial sections of an interview. Generally there was as little as a paragraph per interview of material that was not relevant. The median number of textual invariant nodes each section of text was coded to was three and the average size of a section of text was half an average paragraph. Approximately two thirds of the data was coded before the list of textual invariants became saturated⁴¹ and it took until there were only two remaining case nodes before I could be confident that the content of each of the textual invariant nodes had reached saturation. This is one participant more than was required to reach saturation across all of the interviews in the interviewing process. As I coded the data, I kept notes on the progress of the coding process and on any insights or observations I made about the data.

Although I retained the consolidated list of textual invariants to hand, textual invariant nodes were created as material containing each invariant arose. The consolidated list of textual

⁴⁰ NVivo is a software package used in qualitative research (Richards 2000). NVivo provides a means to code text into nodes that act as containers for the coded text, without losing reference to the original context of the text, while also allowing the researcher to view the entire content of the node in isolation. NVivo nodes are a practical implementation of the nodes concept introduced in section 6.6.

⁴¹ Saturation is reached when new data ceases presenting substantial new material, although new data may confirm existing material.

invariants functioned to prompt me to recognise a textual invariant somewhat earlier through the coding process than I may otherwise have been able. I consider that this substantially reduced the reviewing and reorganising of the textual invariants in the early stages of the coding process. When material identifying a new textual invariant arose, I reviewed all the previously coded interview data to identify any previous sections of text that were relevant.

New textual invariants emerged in principally two ways. The first was simply that there had not been any previous material expressing that textual invariant. Given the broad scope of this data and the number of subgroups involved, it is not surprising that new textual invariants were still emerging in this manner as much as two thirds of the way through the case nodes. Secondly, new textual invariants arose from the material in a case node under consideration, more deeply informing my understanding of the material reviewed in previous case nodes. In this way, textual invariants emerged that were not evident from isolated readings of individual case nodes. This led to a continual clarification of the textual invariant nodes. One case node may not have been enough to draw my attention to a textual invariant. Further case nodes added to my understanding of an aspect of the participants' expression and led me to either include a new textual invariant, become aware that an existing invariant actually represented several invariants, or merge existing invariants. Where I suspected invariants should be merged I reread the content of the nodes concerned before merging them. Generally no rereading of previous case node material was required. Where a node needed to be split into a number of separate invariants, I reread the content of the existing invariant node and recoded it appropriately. Usually, no rereading of previous case node material was required, however, in cases where new invariants were established, I reviewed all previous case node material. If new case node material appeared to contradict existing invariant attribution, in a process similar to the inter-participant validation process, these differences were preserved. Such differences most often led to the development of new textual invariant nodes. Occasionally, this material led to the amalgamation of a number of existing invariant nodes as it became clear that only one invariant was being expressed. Generally, I followed the same processes of review as for instances where new material deepened my understanding of textual invariants.

On several occasions, I devoted time purely to considering textual invariant node attribution. As part of this process, I occasionally either merged invariant nodes or separated the content of a node into a number of new invariants. As the list of textual invariant nodes drew closer to saturating, this process became less necessary. It is noteworthy that when I initially began coding a case node the coding was often very dense. This reflected the fact that the initial part of the interview process often involved the participants covering, in a list-like fashion, the

different aspects of their experience. As I progressed further through each case node, the coding became less dense. More often a passage would only relate to one or two textual invariants. Viewing the coding stripes for each case node in NVivo verifies this. This reflects the saturation process within the interviews in which the participants are suspending, redirecting and verbalising individual invariants to a finer grain of expression. The coding also shows that when, toward the end of the interview process, I asked the participant if there were any other aspects to their experience they wished to express, any further text either states that all aspects have been covered or amounts to repetition of previously covered material.

7.9 Modelling the Invariants: the First Semiotic Analysis

Through the coding process, I established approximately one hundred and twenty saturated textual invariants, each represented by a node. As I reflected on the interviews, the coding process and the content of these nodes, it became clear that the participants were placing greater significance on some of these aspects of their experience as reflected in the respective textual invariants, whereas other invariants referred to less significant aspects of participants' experiences. Each of the invariants was related to the others through complex multidimensional relationships and those invariants that were more significant for the interviewees were often related to a higher than average number of other invariants. Some of the invariants were related to almost every other invariant whereas others related to only a few other invariants. Equally, individual invariants had very significant relationships with specific other invariants and less significant relationships with others.

As an intermediary step in the process of analysing the phenomenal data, I decided to create a model of the relationships between the nodes as an heuristic method by which I could more effectively examine the "dynamic topology of places and connections" through which the nodes related to each other as this had been presented by the participants (Greimas cited in Perron 1987, p.xxix). This descriptive network would name the nodes and the observed relations between the nodes and their points of intersection and disjunction (see section 6.9).

I attempted to draw this descriptive network by hand, considering each of the relationships of opposition or contrariety, contradiction and implication or complementarity for each pair of nodes. Although I spent considerable time trying to refine this model of the data, the nodes were so densely interrelated that I could not visualise enough of the relationships at once to be sure that I was developing an effective model. Nevertheless, there did appear to be considerable structure or clustering within the model. I decided to use some qualitative mathematical

modelling⁴² tools to elucidate the structure of the network, in particular using graph-theoretical clustering as a principal component analysis⁴³ of the set of relationships.

Initially, I considered all the possible relationships between the nodes and decided whether a relationship existed or not. Using a spreadsheet was impractical because there were approximately 7140 pairs of nodes to consider. Instead, I decided to use the graph editor YEd (2007) to create each node and link it to any of the other nodes it related to. To decide whether a relationship existed, I reflected on the data coding process and could generally remember whether and how the two nodes had been connected by the participants. Where reflection still left me uncertain, however, I reread the content of each of the nodes being considered. Each of the node pairs were considered twice, once in each 'direction'. For example, when I was working with the topic node called 'energy', I considered whether this had any form of relationship with each of the other topic nodes including for example, the topic node called 'tired, fatigue', and, likewise, when I was working with the topic node 'tired, fatigue' I considered whether it had any form of relationship with all the other topic nodes including the topic node 'energy'. In this way the relationships between the two topic nodes 'energy' and 'tired, fatigue' were considered in both directions. I started building the graph with the nodes that appeared to be most densely interrelated.

The total relationships graph thus constructed was not apprehensible by eye for two principal reasons: the graph is not inherently spatially embeddable and the nodes are so densely connected that it becomes impossible to parse the descriptive network by eye. An example of a spatially embeddable graph would be the graph derived from a street map where the roads were represented by the edges or links in the graph and the intersections by the nodes. Such a graph is representable in two or three dimensions in such a way that the edges do not cross other edges of the graph. Given that the hand derived model appeared to show that the data contained smaller groups or clusters of nodes and the total relationships graph also appeared to have an underlying structure made up of clusters or groups of nodes, I decided to try and establish whether these clusters were in fact there by calculating the graph's mean clustering coefficient⁴⁴ (Watts 1999, 2003).

⁴² Mathematics is the science of patterns (Steen April 29, 1988). A mathematical model represents essential aspects of a system such that it provides knowledge of that system (Eykhoff 1974). A qualitative mathematical model is one that represents qualitative knowledge about the system.

⁴³ Principal component analyses enable the most significant subdivisions of a superficially undifferentiated (and usually large) collection of data to be identified.

⁴⁴ The clustering co-efficient for a node is the number of links or edges between the set of nodes consisting of that node's immediate neighbours divided by the number of edges or links that could possibly exist between those nodes. Effectively a node's clustering coefficient tells us the probability that the node's neighbours are connected to each other. The mean clustering coefficient for a graph is the mean clustering coefficient. The higher the mean clustering co-efficient the more clustered the graph is. A minimally clustered graph has a coefficient of zero. Such a graph would have a minimum number of links between the

A random graph with the same number of nodes and edges as the total relationships graph would have a clustering coefficient of approximately 0.05; this is the least degree of structure to be expected in a graph of this size. The total relationships graph had a mean clustering coefficient of approximately 0.30 which implied that it was a highly structured graph. It did indeed contain clusters and was an example of a “small world” graph as this is defined by Watts (2003, 1999). The range of node degrees in the total relationships graph was 1-103 with a mode of 5 and a mean of 30. The large clustering coefficient and the mean degree which is much higher than the mode together imply that there are a small number of highly connected nodes, and therefore this is indeed a small world graph⁴⁵. When a cluster analysis is run on a small world graph, one may expect to find a relatively small number of dense clusters. One may also assume that the nodes are highly interrelated (Watts 1999, 2003).

For the cluster analysis of the total relationships graph, I decided to use a modified version of the Kernighan-Lin minimum cut algorithm (Lin and Kernighan 1973). This original algorithm partitions larger and much less clustered graphs into clusters. The modified algorithm is effective for more densely clustered graphs. The modified algorithm is as follows:

1) The modified algorithm presumes that all the edges in the graph can be given a numerical strength. I used zero for no relationship and one for the presence of a relationship. Note that the nature of the relationship (opposition or contrariety, contradiction and implication or complementarity) is not represented, and therefore only the presence or strength of a relationship can influence the result.

2) The algorithm then divides the nodes into a random preliminary set of clusters.

3) The algorithm then labels all the nodes with their node clustering coefficient. For each edge it calculates the product of the clustering coefficient of the nodes joined by the edge and the numerical strength of the edge assigned in Step 1. The result is the edge weight.

4) The algorithm then considers all possible pairs of nodes across the preliminary clusters. If the sum of the weights of the edges connecting each pair of nodes to nodes in other clusters would be decreased if the two nodes were exchanged then the nodes are exchanged. In this way the nodes are exchanged if by doing so the algorithm decreases the weight of those edges that cross between the clusters and increases the weight of those edges within a cluster.

5) If any node is found not to have any neighbours within its cluster it is moved into a cluster where it does have neighbours unless it has no neighbours at all in which case it remains where it is.

nodes or close to no edges whereas a maximally clustered graph would have a clustering coefficient of one and would have the maximum possible edges.

⁴⁵ In a small world graph the longest shortest path between any two nodes (the graph radius) is significantly smaller than the expected length of the longest shortest path between any two nodes for a random graph of the same size.

6) Operations four and five are repeated until there are no more exchanges and no more moves.

7) The result is a set of clusters.

Although the initial clustering results were promising, they were not as clear as I considered possible. The nodes in the clusters seemed somewhat random given what I knew about the strength of the relationships between the nodes. By only allotting a value of zero or one to the relationships between the nodes, I had only signalled whether a relationship existed or not and nothing about its importance. To get more information into the structure of the graph, I decided to weight each of the existing relationships on a scale of one to three where one represented a weak relationship and three represented what I perceived to be a very important or significant relationship (section 6.9). The clustering algorithm was run again using the weighted relationships as input. A one to three weighting of the relationships is not a fine-grained measure, but these results showed that it was enough to produce an approximation to the partitioning of the descriptive network that I was aiming for. This weighting had meant that the clustering process could achieve enough structural clarity for me to derive and refine the remaining structure by hand. I adjusted some of the existing weights, added a small number of new edges and repeated the clustering process, a total of six small adjustments. The resulting clusters were extracted from the adjusted weighted relationships graph for presentation using YEd (2007) and Graphviz (2007). My final version of the descriptive network consists of eleven clusters which are labelled according to the principal isotopy they convey and a graph representing the relationships between these eleven clusters.

7.9.1 Modelling Results

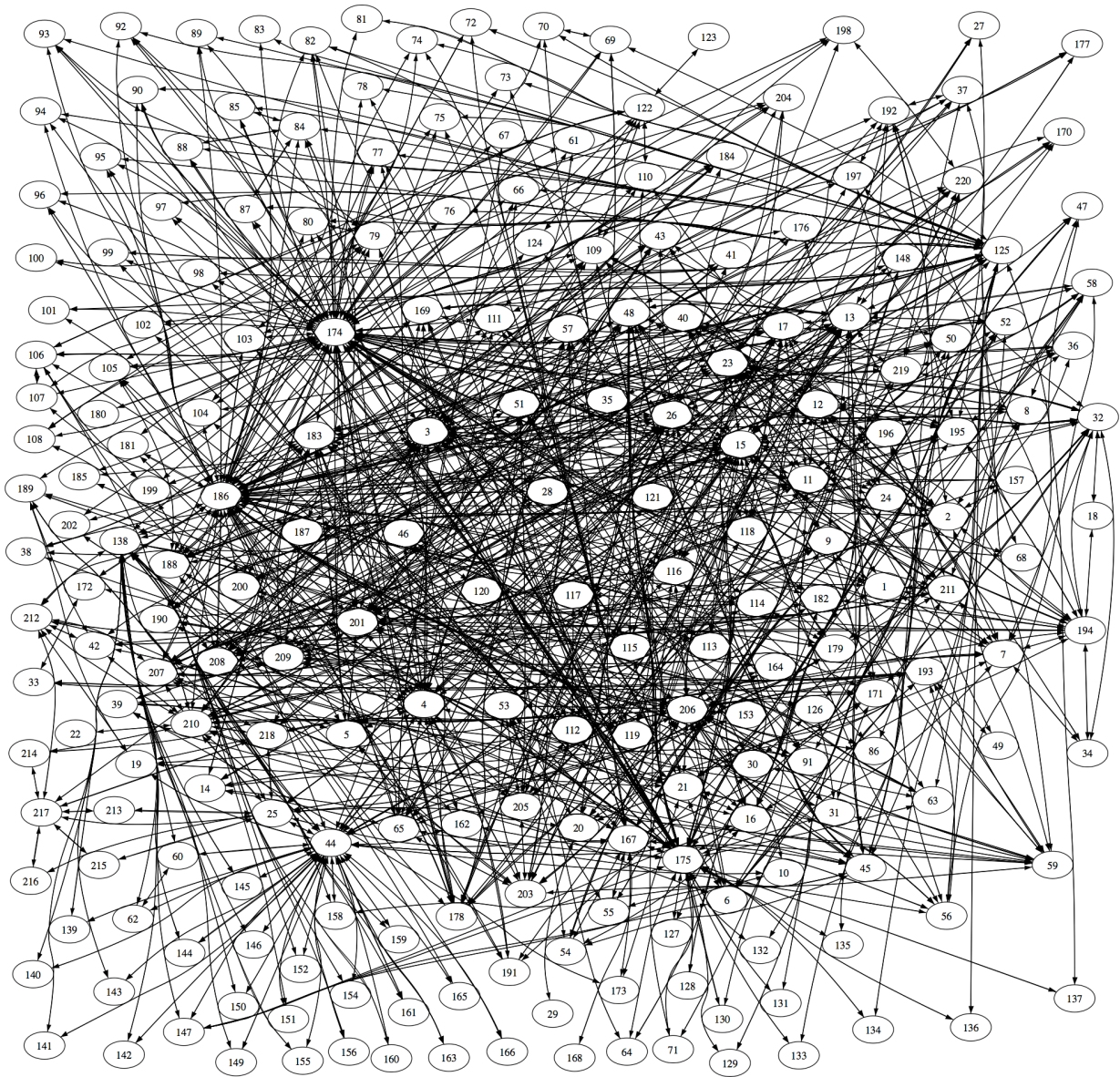


Figure 2: The total weighted relationships graph, including manual adjustments.

See appendix G: for the list of node names as labels are impractical to display.

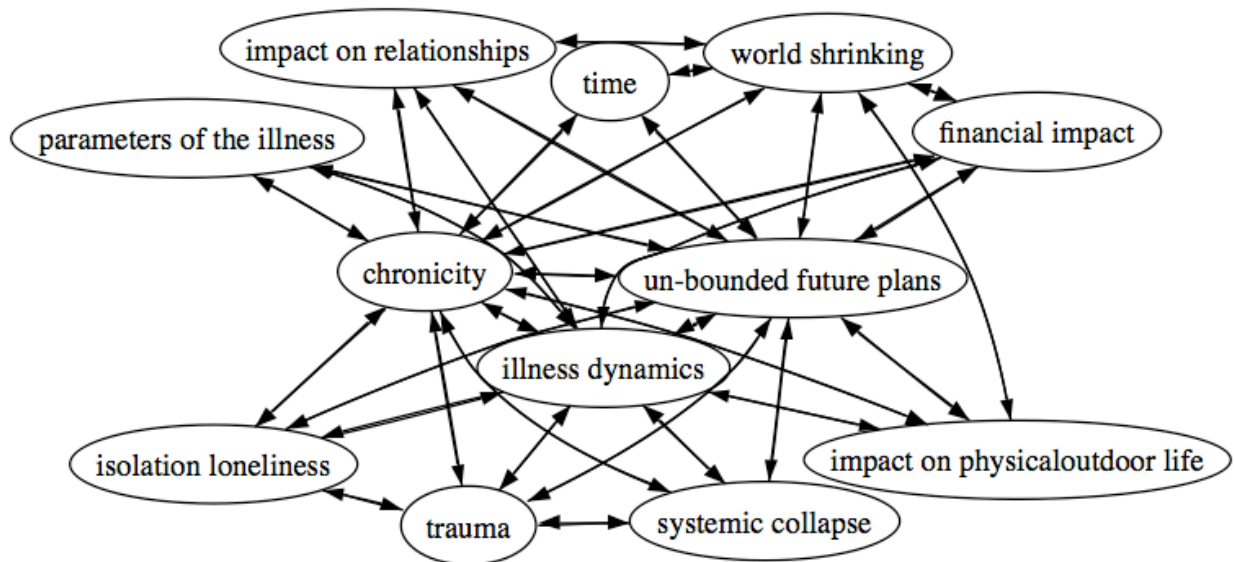


Figure 3: The “unbounded” cluster.

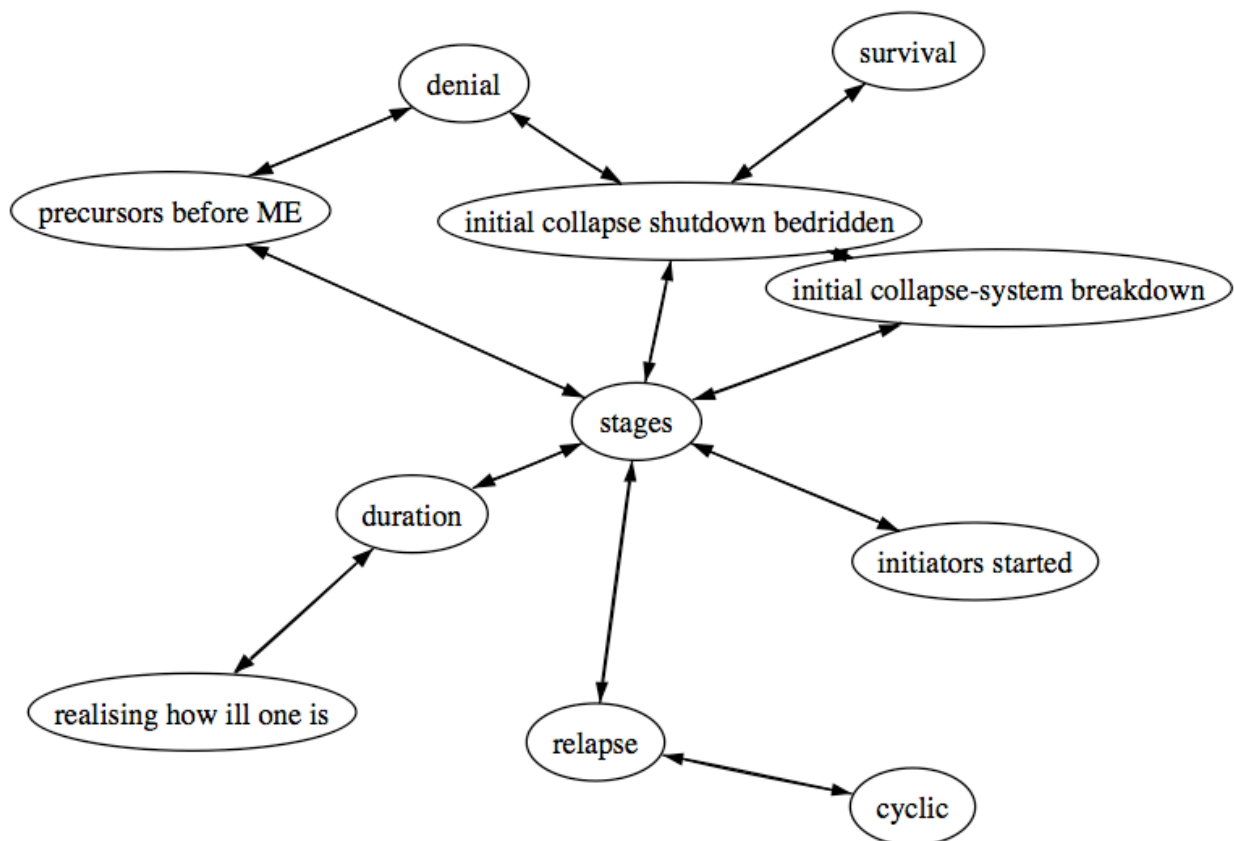


Figure 4: The “stages” cluster.

Figure 5: The “energy” cluster.

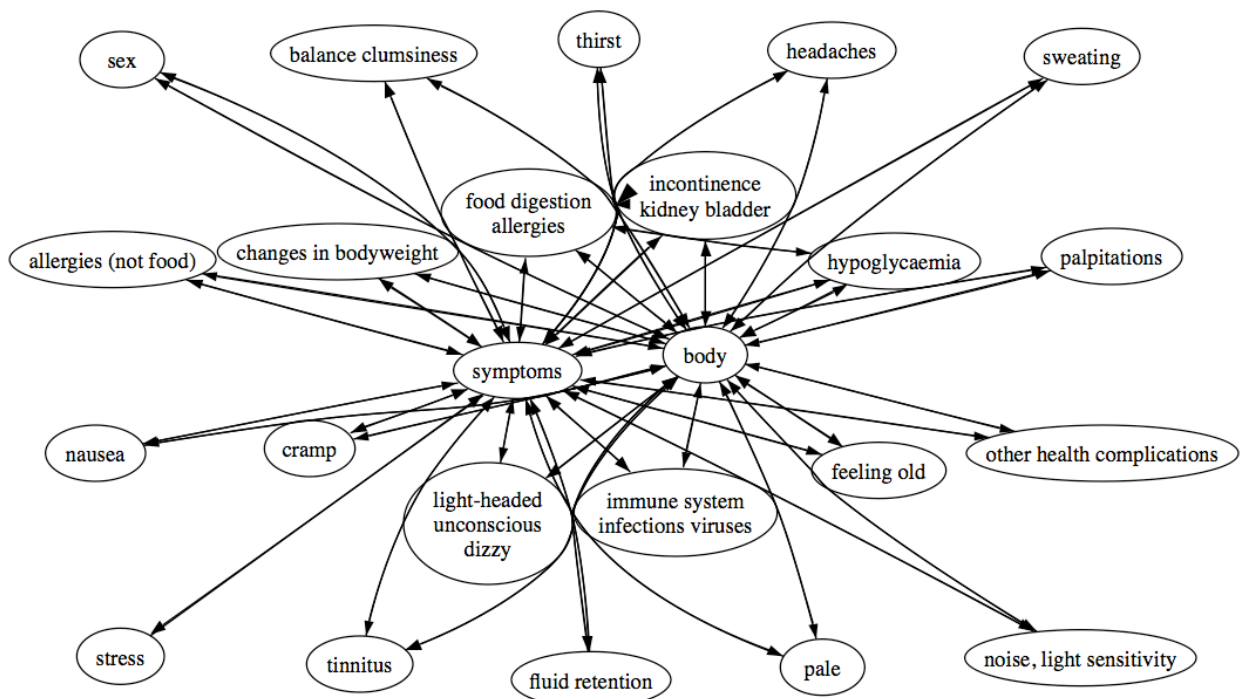


Figure 6: The “body” cluster.

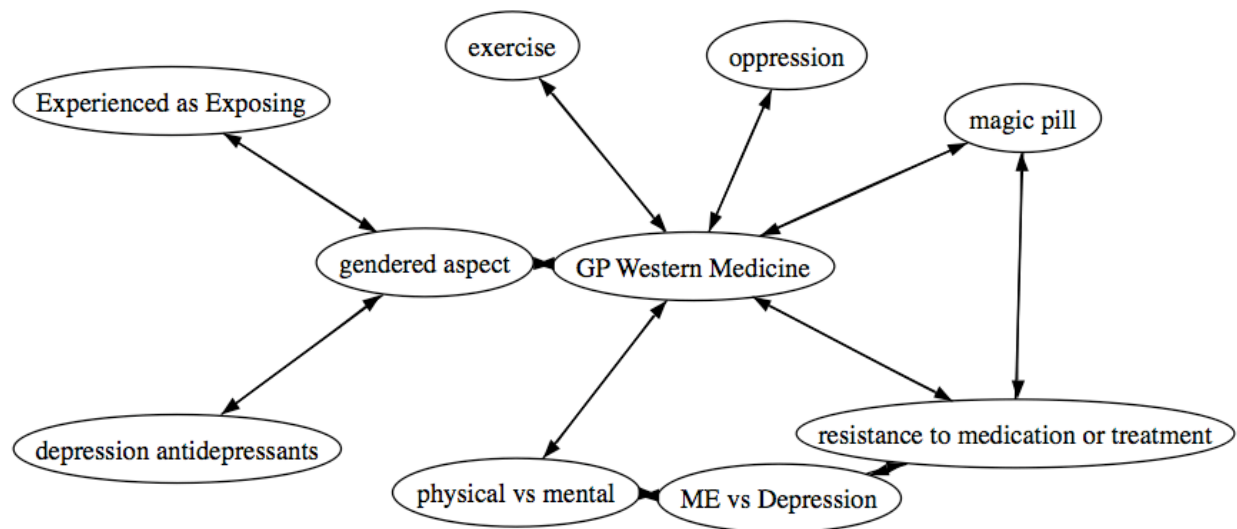


Figure 7: The “biomedicine” cluster.

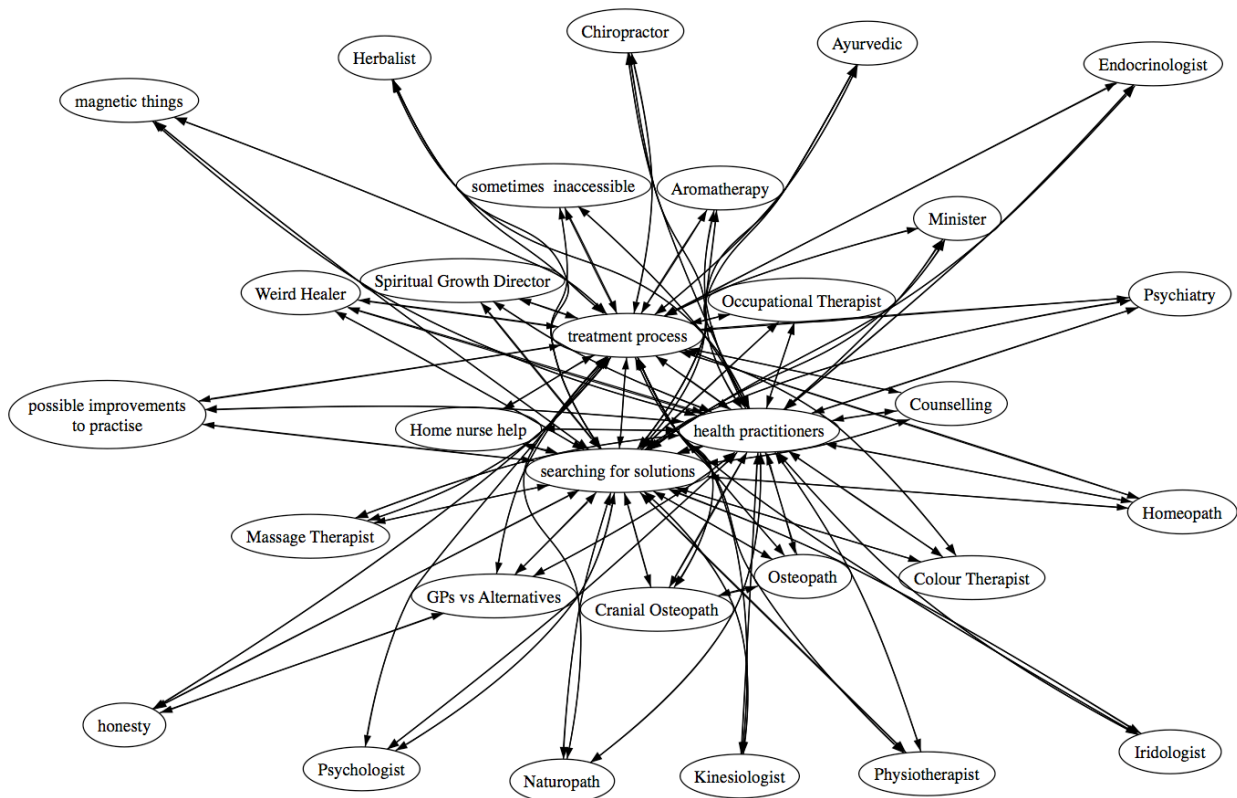


Figure 8: The “searching for solutions” cluster.

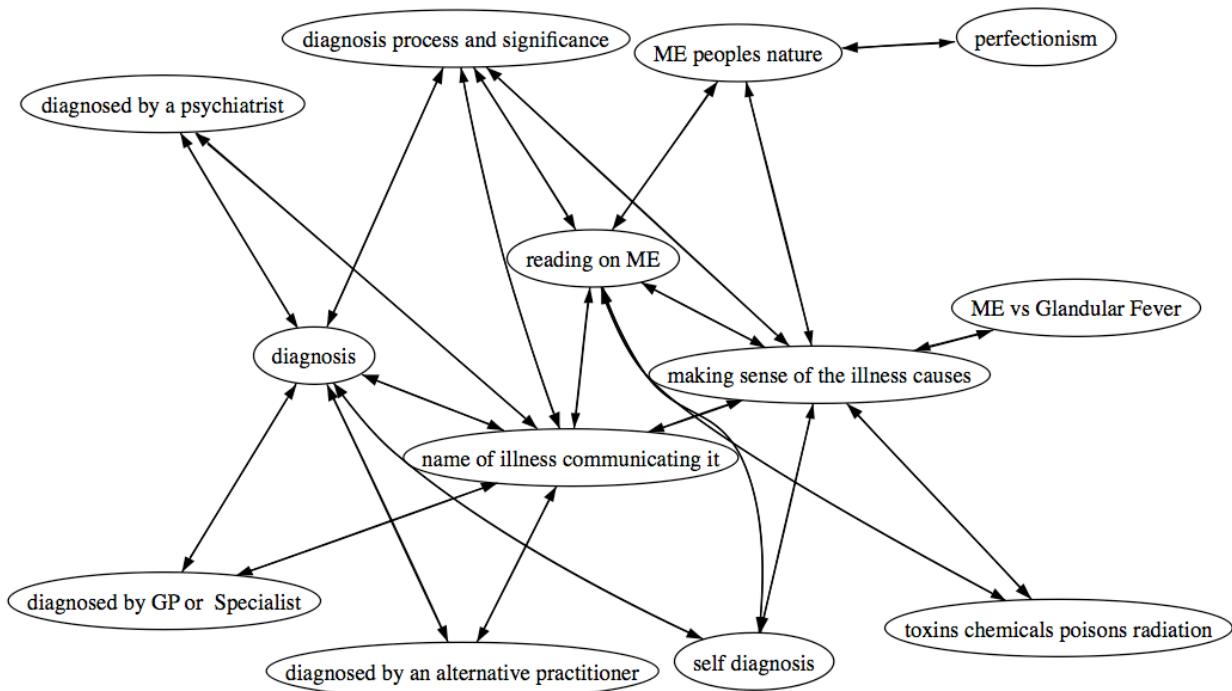


Figure 9: The “making sense” cluster.

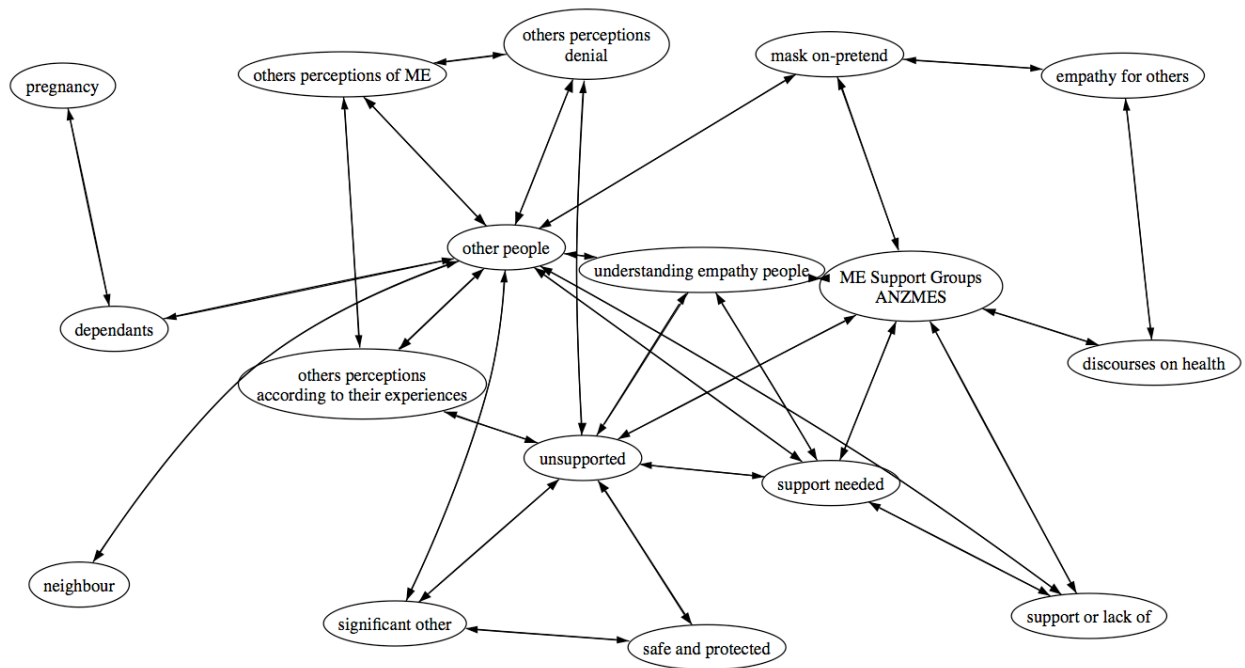


Figure 10: The “other people” cluster.

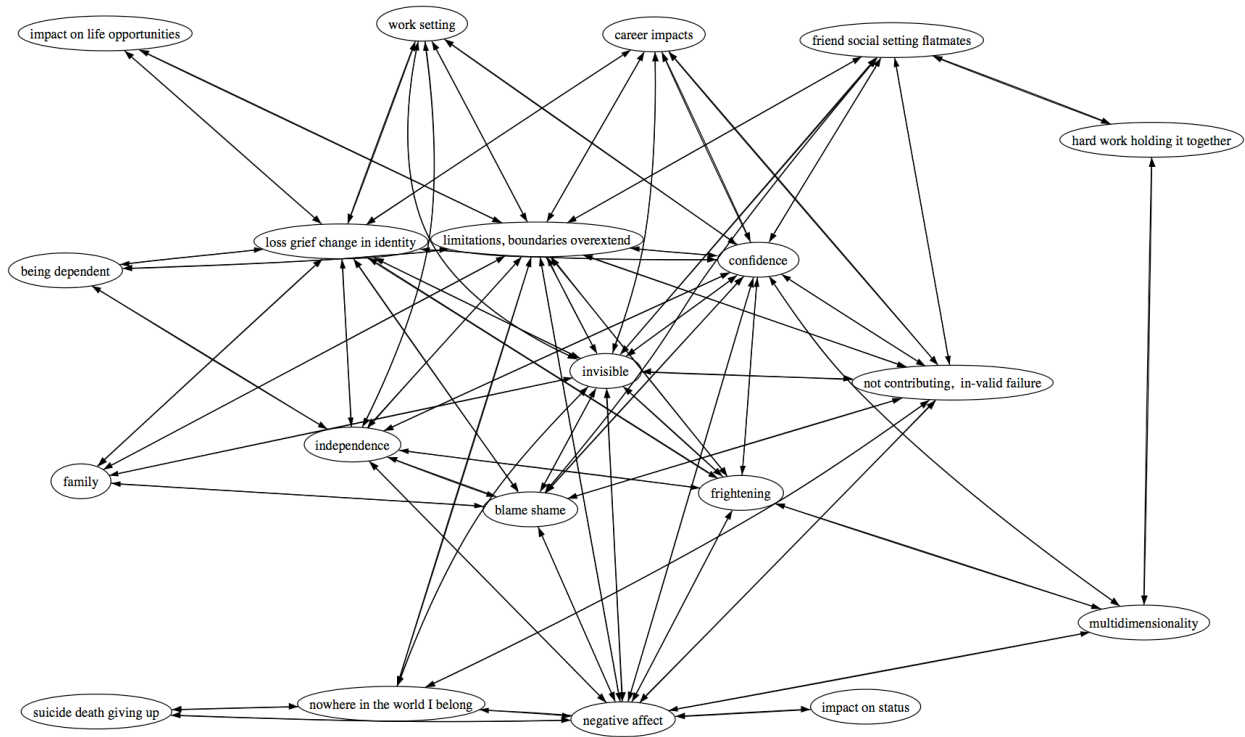


Figure 11: The “impact” cluster.

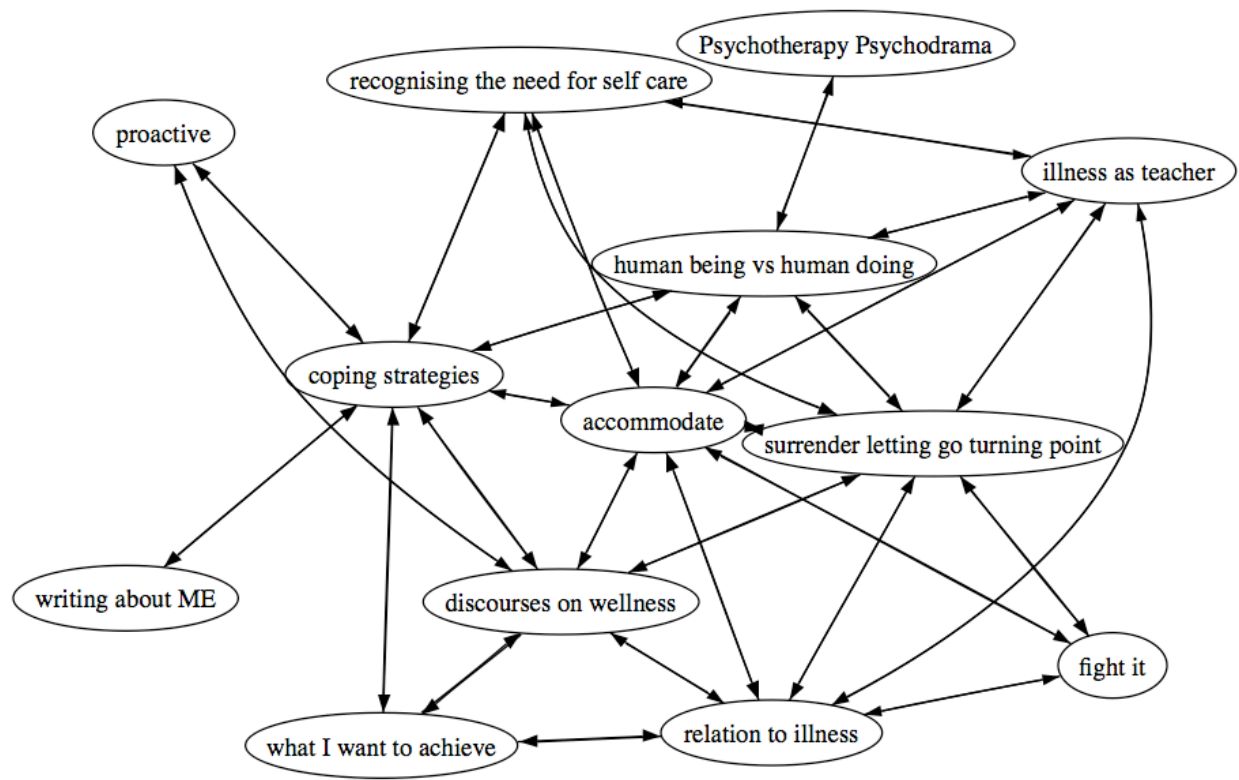


Figure 12: The “coping strategies” cluster.

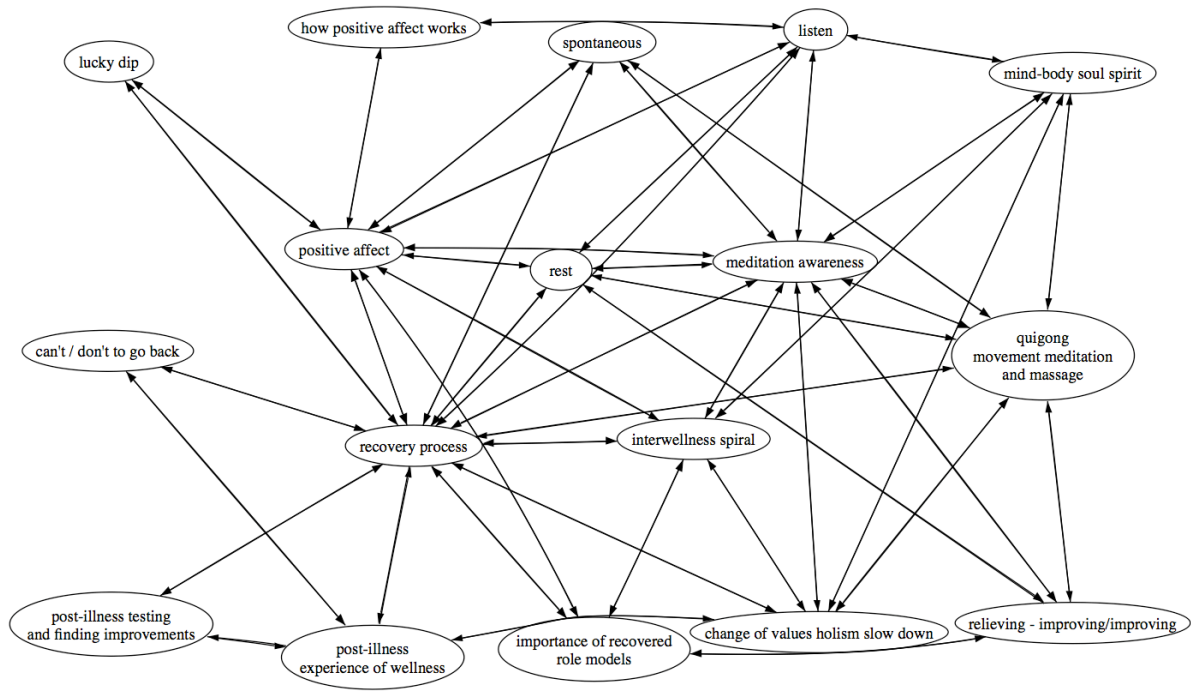


Figure 13: The “recovery” cluster.

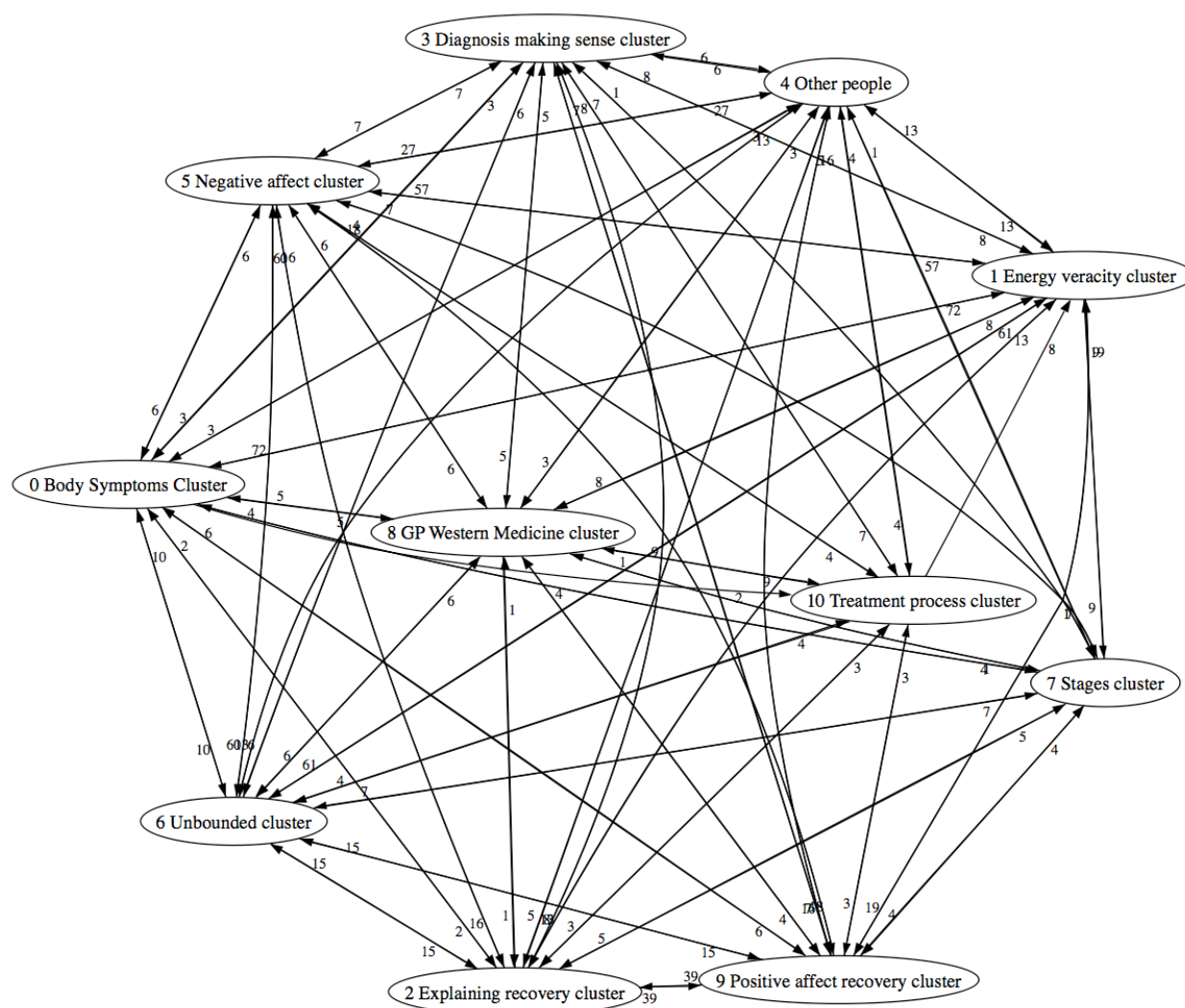


Figure 14: A graph of the relationships between the clusters.

In this graph each node represents a cluster. The edges are labelled with the number of edges from the total relationships graph connecting each pair of clusters.

Chapters 8 through to 11 present an analysis of the data. The analysis presented in chapter 8 draws directly on each of the clusters established above. What this overview of the data reveals is the central importance of the energy isotopy to the participants discourse on CFS. The overview of the data also revealed that the principal differences between the ill and recovered participants related to their concept of self.

7.9.2 Second Semiotic Analysis

The contribution from ill and recovered participants to each of the original nodes established in the first coding process was assayed by number of extracts, number of words in extracts and the actual content examined. Nodes where the contributions were significantly different were identified. Examining in detail the contributions to each of the nodes from the ill and recovered

participant subgroups showed that there were eleven nodes that contained content from only recovered participants and seven nodes that contained content from only ill participants.

Most of the eleven nodes that contained content from recovered interviewees alone were members of the recovery cluster (Figure 13). The self is of central importance to all twenty nodes in this cluster and the self was of central importance to all of the remaining nodes that showed a significant difference in contribution from ill and recovered participant subgroups. There were three clusters that did not contain significant data on the self: “energy”, “body” and “biomedicine”. The contents of the nodes from the other clusters were recoded with a focus on the self (see appendix H:). Chapters 9 and 10 present an in-depth analysis of the participants’ self narratives. The contents of the nodes from the Energy cluster were also recoded more finely (see appendix I:). Chapter 11 presents an in-depth analysis of the Energy cluster.

7.10 Conclusion

A number of comparisons can be made between this method of data generation and analysis and prior first-person research. In this research, I was unable to train participants prior to the interviews; however, participants were given the opportunity to practice the gestures constitutive of *epoche*. Participants were active in the intersubjective development of invariants and variability of account was incorporated into this process and into later analysis. Throughout the interview process both participants and myself as the second-person employed an intersubjective empathic openness.

I consider that the mathematical cluster analysis presented above was necessary to enable me to develop an adequate representation of the descriptive network within which the invariants were presented by the interviewees. Representation here refers to the weak sense described in section 4.12. Qualitative mathematics is used to serve a semiotic objective. That semiotic relationships can have a degree of ‘strength’ or ‘weight’ is clear from Greimas’s work (see section 6.9). For the purpose of this method I graded that strength numerically (0-3) so that the graphs could contain sufficient information for the clustering algorithm to find semiotically relevant structures in this very complex descriptive network and this appears to have been sufficient. The chapters below further the analysis of this data. It may be useful in future research to employ a finer-grained measure and to devise a means by which the nature of the relationship between each pair of nodes could be represented, whether this is one of opposition or contrariety, contradiction and implication or complementarity. With advancements in technology it may now be possible to develop a tool that builds the clusters in a continually cumulative manner alongside the coding process. Such a tool could aid the coder to more quickly identify node relationships, the kinds of node relationships and the subtlety of these relationships.

Documenting the changing cluster pattern as each data set is included in the clustering process could be revealing. Such a cumulative process would need to be used mindfully to avoid premature conclusions being drawn before a genuine level of saturation has been achieved.

Although in this research the strength and kind of semiotic relationships were established manually, Tagarelli and Karypis (2008) give an example of how this may be automated.

This research engages with only one form of expression⁴⁶ or report: verbalisation. Gallagher and Marcel comment with respect to experimental evidence that compared different means of providing report:

If reports are indeed reports of experience then it appears that an experience is not independent of report, but depends on the mode of report. This may mean that the nature of an intended report influences experience, but since in the experiment involving simultaneous reports all three report modes were intended, this cannot be a complete explanation. An alternative and preferred hypothesis is that different ways of reporting have differential access to an experience. (Gallagher and Marcel 1999, p.284)

Anecdotal evidence from my observation of the participants' expression through body language, movement and posture suggests that it may be worthwhile for future research to consider analysing other means of expression such as these for the semantic charge of their content⁴⁷. A number of authors are considering semiotics and discourse analysis in relation to bodily expression (Cobley 2001; Nightingale 1999). This could potentially provide a broader platform of access to the experience. This would require that the researcher build the appropriate level of rapport with the research participants and have the technology available to make use of the data gathered towards this end. For the present research, video taping and analysis of this data was not practically feasible. The slowing of speech and changes in the rhythm of speech, the use of gesture, the variation in the direction of eye movements and eye contact with the researcher, and the level of focus of the interviewees' eyes could be recorded in future research, if the issues explained in section 7.3 can be overcome. Recent developments in the film, television and computer industries would make the coding of visual data possible. An interpretive approach to such forms of expression would need to be developed.

⁴⁶ "Following L. Hjelmslev, we designate by **expression** plane the Saussurian signifier taken in the totality of its articulations, as the recto of a page whose verso would be the signified. ... The expression plane is in a relation of reciprocal presupposition with the content plane, and their union, in the language act, corresponds to semiosis. The distinction between these two planes of language is, in Hjelmslevian theory, logically anterior to the division of each into form and substance. The expression form is thus phonology's object of study, whereas the expression substance belongs to phonetics" (Greimas and Courtés 1979, p.113). This definition of expression is consistent with the enactive approach.

⁴⁷ "The term content is thus synonymous with Saussure's overall signified" (Greimas and Courtés 1979, p.57).

8. An Overview of the Experience of CFS

8.1 Introduction

A portrait of the landscape of the experience of suffering and recovering from CFS as this was expressed by the research participants is presented in sections 8.2 through to 8.12. The chapter weaves a path through the phenomenal invariants discussed by the participants that honours the relationships between these phenomenal invariants as components of importance to the meaning-effect of the discourse as much as the objects⁴⁸ that they connect. Each of sections 8.2 through to 8.12 present and briefly examine content related to one of the eleven clusters established in chapter 7. The phenomenal invariants, represented in the clusters as nodes, are illustrated by examples from interview transcripts. Some phenomenal invariants are comprised of a relatively small number of objects or basic elements. Often, these are components that comprise a narrative within the participants' discourse on CFS. Other phenomenal invariants, such as "energy" are more complex and represent an entire isotopy underpinning the cluster it is found within and also evident throughout the participants' CFS discourse.

Sections 8.2 through to 8.12 are each concluded with brief analytical reflections on what the material in these sections contributes to an understanding of the structure of signification within the participants' discourse on CFS. This analysis begins to introduce the formal dynamical tools (Lutz 2002a, p.149) of Greimasian nomenclature (Greimas and Courtés 1979). For the reader's convenience the relevant definitions for this very specific nomenclature are footnoted on their first occurrence and included in the Glossary. These definitions have been taken from the relevant entries of *Semiotics and Language: An Analytical Dictionary* (Greimas and Courtés 1979). To avoid confusion, it is important to note that this so-called dictionary is in fact "a systematic presentation, in the form of concise and up-to-date reflections, of all aspects of language in this very broadest sense, as semiotic system(s) and/or process(es). Its goal is to review and evaluate the various theories of language, and simultaneously to present a synthesis – or at least a partial one – of the various attempts that have been made to establish this field of knowledge as a coherent theory" (Greimas and Courtés 1979, p.xi). The chapter draws to a close

⁴⁸ "In the framework of epistemological reflection, **object** is the name given to that which is thought or perceived as distinct from the act of thinking (or perceiving) and from the subject who thinks (or perceives) it. This definition – which is not really a definition – suffices to say that only the relation between the knowing subject and the object of knowledge grounds them as existents and as distinct from one another. This is an attitude which seems totally in conformity with the structural approach to semiotics. It is in this sense that we speak of object language or of semiotic entity, by insisting upon the absence of any *a priori* determination of the object other than its relation to the subject. 2. Perceived in this way, the object is but a formal position; it is knowable only by its determinations which are, also, relational in nature. The object is constituted through the establishment of relations (a) between it and other objects; (b) between it considered as a whole and its parts; and (c) between its parts, on the one hand, and the set of relations previously established, on the other. As a result of the construction carried out by the knowing subject, the **semiotic object** is therefore reduced as L. Hjelmslev says, to "intersecting points in these networks of relations" (Greimas and Courtés 1979, p.216). There is a strong parallel between this definition of object, subject and that which is perceived or thought and the experience, experiencer and the relation between them of basic element analysis.

with a discussion of what has been found in each section. This discussion, and the chapter as a whole, provide the context for the later analysis chapters.

Broadly speaking, the sections in this chapter can be divided into three categories. The first category would include those sections that capture the ways in which the participants relate their illness experience most directly. This category includes sections 8.2, An “Unbounded” “Dynamic” “Chronic” Experience, 8.4, Talking about “Energy” States and Struggling with Issues of “Veracity”, 8.5, “Body” States, 8.11, Relating to the Illness and Employing “Coping Strategies” and section 8.12, Recovery. The distinction made by the participants between the material presented in section 8.4 and that of section 8.5 is noteworthy. The second category, material that relates how the participants explain their experience, is presented in section 8.3 “Stages” and “Moments” of “Significance” and 8.8, Making Sense. The remaining four sections, sections 8.6, Interacting with Biomedicine, 8.7, ‘Searching for “Solutions”’, 8.9, “Other People” and 8.10, The “Impact” of CFS, portray experiences that the participants meet as a consequence of suffering from CFS.

8.2 An “Unbounded” “Dynamic” “Chronic” Experience

A key isotopy expressed by the participants is their experience of CFS as “unbounded”⁴⁹ (Figure 3). The “unboundedness” of the illness experience is described in a number of ways. Many of the participants experience the syndrome as “all pervasive” and, for some, “all consuming”.

I3⁵⁰: It impacts everything. Don't underestimate it, it hits every area of anyone's life who's got it.

I8: This [illness] was an all consuming thing, it was just overtaking everything. I couldn't plan to be somewhere tomorrow, or next week, or next month, because I didn't know whether I would be out of bed. Just everyday living was exhausting.

All participants describe CFS as unbounded in terms of its “unpredictability”, the constant and unpredictable fluctuation of the experience of symptoms. A consequence of this unpredictability is the inability to plan general life activities. The participants find this inability to plan very disruptive and many employ a strategy of “going with the flow” to compensate.

I3: With the fluctuations of the illness, you're up one day, down the next, and you just tend to learn to go with the flow and accept what's there. Otherwise you'd just end up an absolute psychological mess.

The participants described these illness dynamics in considerable detail.

I14: Where I'm at fluctuates between probably 40 and 70 percent. Bad days, I'm about 40 percent and good days about 70. Maybe one or two days I might get up, it would be once

⁴⁹ Words and phrases placed in quotation marks in chapters 8 to 11 are those commonly used by the participants.

⁵⁰ Where quoting from participants, I3, for example, represents interviewee number 3. BH is the interviewer.

every two months, and have a day where it's just unbelievable and I race round thinking: 'I'm eighty five percent!' But most of the time, I probably sit on about 60 percent. ... I have a situation where it's day by day. Mine normally changes day by day. Symptoms change day by day.

Many participants reported that their strategy of “going with the flow” was often not accepted by those they needed to interact with on a regular basis, including those closest to them.

A further aspect of the participants' experience of CFS as unbounded, which created difficulty for many participants, particularly in their interactions with others, was the “undefined” nature of the illness process.

I8: Well, it's not like you can be sat down and told, 'Okay, you're an asthmatic. You're going to take this medication when you get an asthma attack and take it three times a day and you'll be fine'. Or, 'You're a diabetic and you've got to take your insulin, so many times, and you'll be fine'.

Similarly, many participants considered the lack of a clear etiology or definition for the syndrome to leave the illness unbounded in ways which others could use to interpret their experience as illegitimate.

I8: This illness, there's not really a lot of proof is there, that, this is what it is. There's a lot of people going, oh, scoff scoff, ho hum.

Many participants commented that the illness, being chronic, is also unbounded in the sense that it is of a potentially “unlimited” duration.

I1: Then it just kept on, and kept on, and kept on, and people are saying, 'Oh you must have M.E.'.

Unlike some chronic illnesses that can either be assumed to be permanent or to resolve in a relatively predictable length of time, CFS has no clear timeframe. Numerous participants found this unbounded chronicity “frightening”. The participants reported that the undefined timeframe for the illness compounded their difficulties in planning both their long and short term future.

I14: I had plans. I wasn't afraid of the future. I didn't fear anything. I fear things now, which I didn't before [CFS]. I fear the future because you don't know what you know. And, of course, you get to my age and everyone's getting married, engaged, in relationships, so you kind of have a fear of being alone, but then you don't really know if you really want to be with someone at the same time. ... I don't really plan past a week. I wouldn't plan a trip overseas for six months down the road, if you know what I mean. I'm not as confident as I used to be and probably fear a lot more things than I used to.

Almost all participants reported that all of the unbounded aspects of the illness impacted on their relationships with “others”, but the chronicity of the syndrome had the greatest impact in this respect and left the participants feeling very “isolated”.

I10: I think that is really, really important, actually. Chronic illness isolates people, that sense of isolation, which of course compounds the illness.

A striking aspect of the participants’ descriptions of the “impacts” of the unbounded nature of the illness experience was what many conveyed as a sense of their “world shrinking”.

I18: I feel like my life has been cut in half and sometimes, it's even a third. What I used to do in a day takes me four days.

I19: It's shrunk even more, I suppose, now, but there's nothing I could do about it. I mean, your world encompasses work and what you do in the evenings, and all those things. Well, I don't do any of those now.

Numerous participants related a dual sense of an increasing restriction on what they can expect to accomplish coupled with a sense that there are fewer world experiences in which they can participate.

I1: It was nice to get into an art class ... and get into the Buddhist Centre ... and just have a little bit of belonging here and there, contact with the world.

The part of their world almost all of the participants consistently expressed the most distress over losing was their working lives.

I19: I love my work. I feel like I'm getting more and more distant from it and I'm never going to get it back. I feel quite panicked about not being at work, especially as the situation I was in was I hadn't completed my training when I got sick.

Without exception, the participants commented that this loss of working life and the experience of the illness in general had a significant negative “financial impact”.

I3: Well, financially I'd probably be about a hundred and fifty grand better off than I am now in assets. ... it just destroys everything right across the board. There's nothing to be gained by it.

I1: My mother had an aneurysm ... and she was expected to die. ... That has been really hard to deal with, because I can't go and see her, because of money. ... I can't look after her and I can't ring her up or write to her because she's not there in that sort of way anymore.

For several participants, the loss of their “physical” lives and their ability to participate in “outdoor” activities was a significant loss of world.

I26: I loved that work. It's a very strong identity I had. I was quite well-known around [place] as a woman [sport] instructor.

For some of the participants, the sense that the “world” was “shrinking” was exacerbated by a “muddled” sense of “time”, particularly during periods of illness which they identified as the most debilitating.

I7: I was very muddled about time, like I thought, ‘But I saw them yesterday’, but it wasn't. It was like three months ago, that kind of stuff. Horrible.

I11: It's hard for me to know what happened when, unless I can link it to a specific event which I know took place at a specific time.

This fluctuating experience of time left the participants feeling disoriented and contributed to the “trauma” that several participants described as an overall consequence of the “impact” of the syndrome on their lives.

I10: When I was writing this morning, I thought, ‘There are many, many ways in which a person can be traumatised and chronic fatigue, it’s traumatic. It doesn’t just traumatise the physical body, but it also traumatises emotionally and psychologically. ... It is trauma’. The central nervous system is very severely traumatised; the only way of keeping going is to force oneself to do whatever is needed for sheer survival, you know. I get images of men who’ve been shell shocked during war, or refugees escaping, people in East Timor, for example, what you do for sheer survival ... All I wanted to do was to curl up in a ball and stay like that. You know, just curl up in a ball and do nothing. That’s what every cell in my body was wanting me to do but I had to force myself to uncurl. I imagine that it’s even more extreme for anyone who is in shellshock or in some way shocked, like in an earthquake or whatever, where you lose everything, you just want to shut down. But you can’t, because it’s either you live or you don’t. ... In those early years particularly, the behaviour patterns that I had put in place for my life that were useful no longer worked. So it was like those resources were no longer available. ... I was forced to design new ways of operating, new ways of living and I’m thinking, again, ‘That’s like people who’ve been chased out of their homes and who are running, running, through the jungle for survival’. They are forced to develop new ways of surviving. And what an incredible thing that is to have to do. And many don’t make it.

Several participants described their illness as a “systemic collapse”. This is clearly illustrated by one participant’s reason for preferring ME as the name for the syndrome.

I28: I actually think ME is better because, what the phrase abbreviates, indicates a complete systemic breakdown, which is what it’s like to experience. Chronic Fatigue Syndrome sounds not really all that serious. It sounds like you’re just getting a little tired every now and then. That doesn’t say anything about getting diarrhoea, it doesn’t say anything about having lesions, or aching bones, or headaches. I just think it’s reductive.

One of the ways most of the participants tried to cope with this unbounded “systemic breakdown” was to place “parameters” on the illness.

I17: It is bad. It’s a real shit of a way to live and facing that really helped because now I think, ‘Right, within those parameters and accepting that, what can I do to make the best of it?’

Most often the participants express these parameters in terms of the “limitations” the illness places on their lives. Sometimes, the participants express that recognising and working with these limitations is a way of easing their experience of the “unpredictable” dynamics of the illness.

I15: It’s a matter of me judging my limits throughout a day, and that’s what keeps me well.

More often, however, these limitations are experienced as deeply restrictive.

I5: Illness is limiting. Health is freedom. Illness limits you in so many ways. It limits your potential, whereas being healthy means having the freedom to develop your potential.

Experiencing the illness as unbounded is reported consistently across all participant subgroups. As an isotopy, unboundedness is abstract⁵¹, connotes dysphoria⁵² and conveys uncertainty⁵³, a not-believing-to-be. There is a consistent sense that, despite their efforts to be in control, the participants find themselves in a state of lack⁵⁴ with respect to control of the unbounded aspects of the illness experience: they are not-able-to-be in control. The unbounded isotopy is present throughout the participants discourse on CFS.

8.3 “Stages” and “Moments” of “Significance”

Alongside their attempts to place limitations and parameters on the unbounded and constantly “fluctuating” experience of the illness, most participants described a number of chronologically ordered “stages” (Figure 4).

In retrospect, numerous participants identified a period of considerable stress “before” their illness and described what they identified as “precursors” to the syndrome.

I17: I think one of the contributing factors towards my ME is that I had my own business. It was a restaurant, I worked 12 hours a day, virtually, seven days a week, and I got really tired. I'd never do that again. I'd be more careful, I'd respect the limitations of my body more.

Distinct from this period of stress, the participants identified some form of “initiator” and a “starting point” to their ill health.

I9: I started to feel really rotten and then, all of a sudden, I sort of went down in a heap. I still associate it with what I thought was a virus at the time.

It is only in retrospect that the participants identify a point at which they consider their illness began and, most typically, at that time the initiator was of no particular significance. In contrast, an “initial” period of “collapse” is almost universally reported as significant and easily identifiable. This initial collapse typically involved a period, lasting between three months to a year, of being totally “bedridden”.

I23: I think it was in January I got a dose of the flu at school. Sent home, told to take six weeks off. It was obviously a bad dose. After six weeks I was not any better and I was bedridden. I could dress myself and that was it and after about six months, I could walk

⁵¹ “Any term, whether belonging to a natural language or a metalanguage, is said to be **abstract** either because its semic density is low, in which case it is opposed to concrete, or because it does not have exteroceptive semes in its sememic composition, in which case it is opposed to figurative. At the level of discursive semantics, a distinction is drawn between the abstract (or thematic) component and the figurative component” (Greimas and Courtés 1979, p.1).

⁵² “**Dysphoria** is the negative term of the thymic category which serves to valorize the semantic microuniverse – by establishing the negative values – and to transform them into axiologies. The thymic category is articulated as *euphoria/dysphoria*, and includes, as a neutral term, *aphoria*” (Greimas and Courtés 1979, p.96).

⁵³ “The contradictory term for certainty within the epistemic modal category, **uncertainty** is the name of the modal structure of *not-believing-to-be*” (Greimas and Courtés 1979, p.355).

⁵⁴ “In the canonic narrative schema as derived from Propp, the lack is the figurative expression of an initial disjunction between the subject and object of the quest: the transformation which brings about their conjunction (or realization) plays a pivotal narrative role (making possible the passage from a state of lack to its liquidation) and corresponds to the decisive test (or performance). Thus we see that the **lack** is not actually a function but a state which, admittedly, is the result of a prior operation of negation (situated at the deep level)” (Greimas and Courtés 1979, p.169).

around the house. Down the passageway to the sunroom and that would be it. After about eight or nine months, I could walk right round the outside of the house and then after a wee while, we had a little block ... that would take say five or ten minutes to walk around and I used to do that and walk round it with my mum.

The participants describe this period of illness as being a matter of “sheer survival”.

I28: I'm still alive. When you're that sick it comes down to basics like that. ‘I can't remember anything said to me, and I can't speak to anybody. I'm alive, and that's pretty much all I've got, just that I know I'm alive. I'm not sure what reality is, things are fairly confused’ ... There's really not much left, apart from the fact that you exist. That's survival, it's just survival, it's not anything else.

All participants found the “duration” of the illness difficult to describe, regardless of whether they had recovered prior to the interviews. Some describe a “cyclic pattern” to their symptoms.

I20: Awful symptoms that go along with it, and they are cyclical symptoms, they run in cycles.

The majority of the participants, however, talk in terms of the “daily” and “weekly” fluctuation of their symptoms and the limitations the syndrome places on them. Similarly, the participants who had recovered consistently conveyed that there was no definable pattern to their “recovery”, rather, they described this as something very gradual.

There are a number of “moments” during the duration of the illness that the participants described as “significant”. Some of the participants described wanting to “deny” the illness entirely.

I7: I spent a lot of time in denial, like, ‘This is not happening to me. I'm just, this is not going to happen, this isn't happening to me, [laughing] whatever it is, it's not happening to me’.

I9: I just went into a state of denial, really, but, all the time I felt rotten, I was hunting around for a cure.

Many of the participants described a moment in which they “realised how ill” they were.

I9: I can remember one vivid incident that just blew me away. I went to town. I'm walking around like a corpse ... I went into Woolworths to buy a notebook ... and I saw this friend of mine ... and I saw her and I knew that I knew her and I didn't know who she was. I knew that someone who was fairly significant in my circle of friends was in front of me, and I didn't know who they were. I didn't know what her name was. Wasn't like I forgot her name, it was like there was no point searching for her name. Do you know what I mean? Like I just, I didn't know who she was, somebody in my life and I didn't know and I was aghast. ... It was scary. I got out of there and got home and said to myself ‘you are too sick to even be vertical. Don't try and negotiate yourself through town’. So that was a turning point for me really.

By far the most significant stage the participants relate, one that is as universal in their stories as the initial collapse and period of being bedridden, is when the participants have

experienced a “relapse” of their perceived level of health. The potential for a relapse is often the most limiting factor in the participants’ illness experience, beyond difficulties with finances or organisational issues. This is clearly illustrated in one participant’s process of weighing up the “pros” and “cons” of an overseas trip to visit family.

I11: [laughs] Monetary cost notwithstanding, there was a possible extreme cost. That would have been for me to have had a relapse or a permanent loss of some portion of what I was able to do. The more likely cost was that I would have a period of time when I was unable to function at my previous level. But having [partner’s name] and looking after myself and eating properly and doing all the things that we know we’re supposed to do for ourselves [it was possible] that I would simply come back up. And that proved to be the case. But there was always a possibility that I would have a major relapse.

The potential for a relapse to occur is conveyed to be unbounded and particularly unpredictable. Even participants who felt they had been symptom free for several years were still afraid that they might relapse. This fear of the syndrome returning characterised a post-illness sense of wellness where the participants found it difficult to see any clear point by which the illness had ended.

The stages of before the illness, being bedridden, duration of illness and relapse and significant moments of denial and realising illness are reported consistently across all the participant subgroups, although the participants who were ill at the time of the interviews tended to speak more about before the illness than those who had recovered. Although recovered participants related their recovery this was not described as a stage. This reflects the very gradual, indefinable and largely unidentifiable character of the recovery process. Recovery is discussed in more detail in section 8.12. The stages isotopy is one of the few isotopes that provides the participants’ narratives with coherence⁵⁵ and a certainty⁵⁶ that contrasts with the uncertainty expressed through the unbounded isotopy. Within the stages isotopy, however, relapse connotes uncertainty. Although the isotopy of stages is presented as a pragmatic⁵⁷ chronology, this chronology demonstrates significant temporal disruption. The stages isotopy reflects dysphoric processes of transformation.

8.4 Talking about “Energy” States and Struggling with Issues of “Veracity”

The most central and most common isotopy related by all participants was the “energy” isotopy (Figure 5). This section presents an initial analysis of this isotopy. Chapter 11 provides a more

⁵⁵ “The term **coherence** is used colloquially to characterize a doctrine, a thought system, or a theory, all of the parts of which hold solidly together” (Greimas and Courtés 1979, p.35).

⁵⁶ “**Certainty** is the name of the positive term of the epistemic modal category the syntactic definition of which is *believing to be*. As opposed to evidence, certainty presupposes the exercise of interpretive doing, of which it is one of the possible consequences” (Greimas and Courtés 1979, p.28).

⁵⁷ “The pragmatic dimension, recognized in narratives, corresponds roughly to the descriptions which are made there of signifying somatic behaviors, organized into programs and taken by the enunciate as ‘events’ independently of their possible utilization at the level of knowing” (Greimas and Courtés 1979, p.240).

in-depth analysis of “energy”. For all of the participants, the experience of their energy fluctuating corresponded with the “illness dynamics” they described as limiting and unpredictable. All participants commented that “overtaxing” their energy could “potentially” “bring on” a relapse.

The majority of the participants described a number of “symptoms” as consequent to the state of their energy, rather than considering these symptoms to be symptomatic of a particular somatic dysfunction. “Fatigue” is the most common example of this relationship. Without exception, when the participants described their experience of fatigue, they consistently related the extremity of the fatigue. It was not simple “tiredness”, but rather a sense of complete “exhaustion” and underlying this exhaustion was a “lack” of “energy”.

I5: I remember the absolute exhaustion of it all. I remember also, one of those sayings was that, tiredness is a luxury I've never had, it's exhaustion. I remember trying to eat an orange and I could hardly lift the orange up. I remember I just had, sort of, very little energy. I was just lying like that [propped up on side]. I thought that's taking far too much energy out of my hands. I just have to lie, like that [on side], totally zonked.

It was this state of lack and the resulting extremity of the fatigue that made the fatigue something different to the everyday experience of tiredness. One participant described their exhaustion as a “giant” weighing them down and making it difficult for them to “breathe”.

I1: When I'm very tired, I have this feeling of something on my chest, which I picture as a giant, and it's pressing me down, and it's quite hard to breathe. ... So I lay down flat, and didn't read or listen to the radio or anything, I just lay with a lovely cat and breathed and slowly came right.

This difficulty with breathing is very different to the shortness of breath some of the participants described when they experienced “anxiety” or “panic attacks”. The most extreme case of this exhaustion was related by one of the participants from Wellington.

I1: I was so, so weak that I had to have all my food cut up. I couldn't lift a fork to my mouth to feed myself. I had a wonderful home help at the time and she went off to a Chinese Takeaway and got some plastic spoons. It was even touch and go whether I had the strength to be able to lift a plastic spoon of cut up food to my mouth. I couldn't lift a fork, I couldn't lift a plate, I couldn't lift a cup, I couldn't open the fridge. I can remember I used to have a home help ... come over each [morning] and put my porridge on my lap. She would make my porridge and then bring it through to me and put it on my lap and I would then eat it. I used to have another home help arrive at lunch time, and she would cut up my lunch and put that on my lap. She would heat up soup for me, leave it in a thermos. She couldn't do up the lid of the thermos, because I couldn't undo it, and we had straws in all my cups. I couldn't lift a cup. And then I was just very, very fortunate that that same home help had another job in [place] and, on the way home at night, she would just come in the door, draw my curtains, put my food in the microwave, cut it up, and then put that on my lap. And I would go to bed in a tracksuit. ... And so I couldn't turn on a tape recorder, I couldn't hold a magazine.

Many of the participants experienced fatigue as a feeling of “weakness”. This weakness was not necessarily always present. It could “come on” suddenly after a period of relatively normal functioning or could be present consistently across days, weeks or months at a time.

I1: I drove downtown to the library and had a wonderful time for an hour and I just sort of felt, I was sitting there trying to write, as if energy was draining out of my big toe. That's how I pictured it, I thought: ‘Oh, it's draining out, I've got to get home’. I knew that I had to get in my car, and drive home while I still could. So it's like a trickling away, a draining, a loss of energy, and it's just the approach of weakness. Can be mental or physical, too.

The participants commented that this weakness left them “feeling old” and “pale”. According to these participants, the weakness they experience results not from dysfunctional muscles or inadequate blood sugar but, rather, from a “draining away” of energy.

Several of the affected participants referred to an aspect of the physical weakness as “jelly legs” and commented that the weakness was accompanied with a sense of “numbness” or “closing down”. Jelly legs and general physical weakness made it difficult for the participants to “walk” and navigate the world. For some of the participants, this weakness was accompanied by a “tingling” sensation similar to pins and needles.

I14: I've got a bit of it [weakness] now in my hands today. Holding a pen can be difficult, like I can't write when it's like that. So you've not only got pins and needles in your legs, you've got total weakness so your hands shake. They feel like they're shaking, your legs, jelly legs as I call them, shake, so the energy level's not there anyway and that's when the tingling and the numbness comes in.

Again jelly legs, tingling and numbness, as expressions of physical weakness, are underpinned by a lack of energy. The participants found this degree of weakness frightening and at times the numbness, in particular, seemed to apply to all their senses to such an extent that they felt they were no longer sensing the whole of the world around them. A recovered participant described her surprise as this numbing of her senses lifted.

I10: The vividness of everything around me, you know, colours, it was just incredible the greens and the colours of flowers, and I hadn't realised, because it had come on so gradually, that I had lost the ability to see vividly and to hear, like music and everything. Suddenly my senses, it was like I got them back. It was incredible.

For many of the participants a lack of energy was experienced as a sense of physical “heaviness” and a lack of “strength”.

I28: No energy ... you feel like your limbs are very heavy, and everything is very sluggish, almost like moving through syrup. Flat can vary, but on the whole, it's just how it sounds. No energy, no spark, slow.

I26: That unpredictability, unreliability, loss of energy, loss of strength.

The experience of a lack of energy was described by several participants as if they were “dragging a rock”.

I20: Energy has just been a problem for so long. It's just something that you haven't got. You just don't have it. You put on a front, you act as though you've got energy and you put it on and you haven't got it, you just haven't got it there. It's just not there. You know it's just not there, not there anymore. You get out and you do what you have to do, but you haven't got it there. You're pushing against it all the time, pushing as though, before you start everything, you've got to move this great rock and push it with you. Get it mobile and push it with you. It's not easy.

Many of the participants used “having” or “lacking” “stamina” as a measure of “how much” energy they had. When they had “enough” energy they had the stamina to do things without worrying about their “energy levels” and they had the energy to be “spontaneous”. A lack of energy, however, would lead to a lack of stamina.

I26: Stamina: if I can keep going, without any thought of, ‘I'm using energy’ ... spontaneity, as well. If it's spontaneous and I can just keep going then I've got energy, whether it's physical or mental.

For some participants, a lack of energy was associated with muscle “cramp”.

I14: Especially when you wake up, you can feel it in the night, too. Can feel the pins and needles and the cramping of the muscles and things like that and it's not a hard cramping. It's just a constant cramp that just sits in your muscles.

Many participants also relate experiences of “pain”. For the majority of the participants, the most common experience of pain is an amorphous “aching pain” that reflects a very “low” energy state and is present simultaneously or alternately in many areas of the body.

I1: Everything aches. When I was first getting this, and it started with glandular fever, but I didn't know what I was getting. I thought it might be Rheumatic Fever because I had a very great pain along my shins. I can't remember whether it was my arms as well. Legs have been very achy at times, and at times walking I've just had the picture in my mind of bones being broken, like a leg snapped off and trying to walk on the crumpled bone left, if it's been really painful. But that's very fleeting, it comes and goes. What aches, seems to ache incessantly, is my back, all over. I have a lot of trouble with my arms, but that didn't come on until quite a few years into it. I get certain headaches which I didn't used to get before, so that can be part of it. That, yeah, that covers just about everything really. My toes don't ache [laugh]. Sometimes everything, the face, everything, it's just an extreme fatigue, I guess.

This amorphous pain was sometimes accompanied by a number of more specific pain experiences such as “muscle”, “joint” and “kidney pain”. These more specifically located pains were experienced both in isolation and with aching pain and by participants who did not experience aching pain.

I18: I generally get very fatigued, have a lot of pain, which is mainly muscle and joint pain.

I7: I was so scared, I was terrified. Thought I was going to die. I didn't believe that you could be in that much pain and not die. And I had a lot of kidney pain so it's like knives, you know, stabbing into your back. It was just unbelievable.

For several participants, pain experiences could become “sharp”, “burning” or “very intense”. The participants found the intensity of this pain frightening to the extent that some participants felt the pain could make them “crazy”.

I13: Hands and hips are sharp, intense pains, and there's really not a lot I can do about them. Nothing I take helps ... I know they describe arthritis as like bits of glass put into the joints. That's how my hips and my hands feel. ... It can feel hot, throbbing, on a scale of one of ten, and ten being my hands and my hips, I'd say, everything else would be a seven, just a throbbing, hot, pain. Like a burn.

I7: I was in pain, you know, that kind of pain can make you crazy.

All the symptoms described above have an apparently somatic dimension. The participants often describe these symptoms alongside and sometimes inseparably from states more apparently emotional. Some of the participants, for instance, described experiencing a lack of energy that literally brought them to “tears”:

I15: My energy level was at such a low ebb I cried, you know what you feel like when you've been emotionally drained? With not much energy left, it just toppled the system.

I1: I was living with a partner for a while and I think he got very used to this. We would go out on Saturday mornings to the library and the supermarket and we both would know that I wouldn't be able to do everything on the list, but I'd be able to do some things. But even so, it was a struggle and I'd always be in tears by the time we got home. I'd need food, I'd need to lie down and I'd just be drained.

A small number of participants described occasions where their lack of energy was associated with “panic attacks”.

I5: I was really sick. My mother wanted to take me to town. I had a panic attack. I just couldn't do it, just like eh no, too sick, don't want to go. I just couldn't get dressed and get my clothes on and get in the car. I think I got that far, ... I just was too ill and she just kept going, ‘come on you can do it’ and I think if you over exert yourself too soon, panic is exactly what happens. Your body is not ready to do those things and I think that is what was happening.

A larger number of the participants commented that a consistently low level of energy would leave them with a constantly present level of “anxiety”.

I14: Quite bad in the morning. Anxiety's bad in the morning, nausea, headaches and just energy levels are low and just actually cranking up the muscles and joints ... I get quite bad anxiety, quite fretting because I'm so ill, all I want is to be in bed sleeping, just so tired that all I want to do is sleep.

Several of these participants described their anxiety as similar to “agoraphobia” on some occasions.

I5: Agoraphobia ... Right. I was walking across the park, and I could feel my energy draining but I thought: 'Oh no I'll get there, but I won't be doing this again in a hurry'. It just seemed to just drain away and then, I didn't know whether I was going to fall down, or fall in a hole, I think my heart was beating a bit but not, not really pounding or anything. I suppose there was panic. There was a bit of panic but not, not wild panic, and I just seemed to literally crash, you know, I felt like I was just crashing, crashing down, everything was just crashing, and I think I spent the next two months in bed. That was not from the agoraphobia, but everything else just went as well.

Lacking energy also had a significant and direct “emotional impact”.

I8: Emotionally, it's a shocking illness. There's nothing tangible to grasp with it. There's nothing. ... Yes, emotionally draining. You really turn yourself inside out. You feel like you're going insane.

Although less directly associated with the participants' perceived energy levels than panic or anxiety, this emotional impact was still a very significant aspect of the participants experience. It is discussed in more detail in section 8.10.

Alongside the physical and emotional consequences of lacking energy, the participants described “mental” or “cognitive” “breakdowns”. Almost ubiquitous in their descriptions was the experience of “brain fog” and “memory problems”.

I7: I had absolute brain fog, could hardly think, you know. The fact that I got myself overseas was a bit of a miracle. I couldn't connect my thoughts together. That was frightening. My memory was all over the place, so I couldn't remember things. Short-term memory just blew out. I had very confused thinking.

Several participants related brain fog to “dyslexia” and almost all described difficulties resulting from the brain fog which included problems with “reading” and “comprehension”, “talking” and “listening”.

I15: I have, like, dyslexic problems and when I'm doing business letters ... I'll write a letter and it could be three times over ... I quite often leave words out, letters off, an extra letter in and, when you go to re-read it, it doesn't make sense, whatever. For a friend, they would understand, but not a business letter. It's nothing for me to rewrite something three times ... so I think probably that, for me, is the most frustrating because I've learnt to cope within the other limits as it were ... I try to tell myself “well, it's a symptom”. I try to be gentle on myself but it's not all that easy. ... I'd read a paragraph and have to read it again ... To read a sentence and at the end of it, think: 'I have no idea what that was about'. I mean, that's really scary, I find that really scary. So I'd read it again and that was how I would read. I'd read a paragraph or I'd start a chapter and then when I picked the book up again I couldn't remember where I'd left off and I'd go back and have to read it again.

BH: Can you describe that “verbal stuff”?

I15: [Laughs] This very interview. Trying to express in words what I want to say. It's there in my head but I can't get it into words.

I1: Sometimes, if I've been talking and using my brain, listening or talking, I can get to the point of tears because I'm so tired. And I can't understand anymore what people might be saying.

These difficulties were evident both during the interviews and in the interview transcripts. It was common for participants to struggle to retain the strand of their own accounts or simply completely “lose track” of the point they were relating during an interview. The participants assert that these difficulties with talking and listening had a significant negative impact on their ability to “relate” to others and “compounded” their sense of isolation.

Almost all participants described “sleep disturbances”. A few participants described “vivid” and “disturbing” “dreams” as aspects of the mental or cognitive problems caused by a lack of energy. Almost without exception, the participants describe sleeping for fourteen to eighteen hours a day in the bedridden stage of the illness.

I1: I seem to be very sleepy at the moment, and, after two or three or four hours out of bed doing things, or maybe sitting down and doing things, I have to go back to bed and sleep ... If I get up at seven: feed the cats, and do a few things, and if the sun's shining I sit in it, in here. I might have to go back to bed at nine and have a really deep sleep for an hour. So, if I can keep doing that, I can keep going, but if I'm deprived of lying down, like I have to lie down to do it... just a wreck really.

The dreams that accompanied this extended sleeping, for a few of the participants, were often so vivid that they added to the participants “confused” sense of “time” and world boundaries by blurring the boundary between waking and sleeping life and the distinction between the conscious and unconscious mind.

I28: If you exist in the dream state all the time, except for a very few hours of the day, and you're very foggy, in terms of your perception anyway, because of the effects of the illness, it can become, especially with the memory effects, as you look back on the day, previously, for instance, very hard to remember what was a dream and what actually happened.

Throughout the duration of the illness, a number of participants described regularly experiencing a state where they did not have enough energy to sleep. Sometimes this was accompanied with a sense that their “mind” was “overactive” and would not allow them to “rest”.

I5: Energy level is not good, poor, I'd say or just above: poor plus. My mental, I'm having trouble with over these last few months. It's when my brain gets over-exerted, part of it won't turn off, I have trouble sleeping.

The participants also described a lack of “good quality” sleep.

I13: Still exhausted. Feel like I haven't had that decent sleep, like that deep sleep, where you sort of get back your energy.

Whether lacking energy created sleep disturbances, “brain fog”, “memory problems” or difficulties with reading, listening or talking to others, the anxiety or the panic attacks they described, the participants unanimously insisted that these symptoms of low energy were the affect on their mind of a diseased “physical body”.

I28: I believe strongly that nobody wills this sort of thing on themselves. I think, perhaps, there is a character that is predisposed to having ME, a high achiever. Somebody who pushes themselves will tend to get it simply because they've exhausted their body's defences and that has opened them up to whatever this illness is. I don't think a mental state causes the disease. I think the disease can cause disastrous mental states, right, and what I found in the medical profession was a rank refusal to consider evidence that demonstrated that.

Many participants described coming to this conclusion after considering and undergoing counselling, a course of antidepressants or other psychoactive drugs. None reported experiencing any benefits from such medication. Numerous participants reported that, their opinion that it was their lack of energy that was creating their symptoms and a diseased physical body led to conflict between them and health practitioners, particularly, but not exclusively, members of the biomedical professions.

When many of the participants were confronted with a negative response to their understanding of the illness as energetically and physically originated, participants reported that this tended to contribute to their sense that the “veracity” of their experience was being questioned, whether this was by those close to them or individuals they sought help or advice from. Several participants described the difficulties they faced when interacting with WINZ⁵⁸ and health insurance companies due to the poorly understood status of the CFS diagnosis.

I2: I wrote a letter of complaint and she wrote me a letter back basically telling me I was wrong and they wanted me to have an assessment by a psychologist. So, of course, I'm like, what the hell's going on here? I complain, they tell me I have to go to a psychologist like, what's the connection? Am I kind of being marginalised here ... I've had letters from them saying you have to go to this psychologist because there are psychological aspects to ME ... Then they he sent me this form [from] this guy before I went to see him to fill out and it was all these, I forget what they call it, it's one of these psychological tests. Basically, all sorts of really weird questions, like, do I have a problem with drugs or, have I've crossed the Atlantic fifty times this year?. All these really weird questions. I'm thinking: 'well what are they trying to get at here?' Like, I don't have a mental illness, I have ME, and so I sent the damn thing back, and, he did this report, basically, and said there was nothing wrong with me. I was slightly histrionic and, what's the other one, basically vain.

Many participants expressed that such questioning of the nature of the syndrome was often a way to question the “reality” of their “suffering”. The participants commented that few professionals were prepared to engage with their understanding of energy.

In contrast to most other professionals, several participants reported that their interactions with neurologists, rheumatologists and practitioners of Traditional Chinese Medicine gave them a sense that their suffering was “acknowledged” and “understood”. The participants drew upon these practitioners’ discourses to explain their experiences.

⁵⁸ Work and Income New Zealand is the government department responsible for providing financial aid for sickness beneficiaries.

I28: The neurologist who tested me said that I'd lost my long term, short term, and recall paths. Right across the spectrum of memory, everything was gone and she said it was quite common with glandular fever. She didn't talk in terms of ME.

I27: The rheumatologist I went to was the exact opposite. She was really very pleasant, interested. I mean, even if she'd given me a negative diagnosis, I would not have minded it coming from her because she was thorough, she checked everything, referred to all the notes that I had, actually did a physical examination, which the other one had skipped. With her, it felt like you were making some progress, that she was actually interested in giving you a diagnosis, at least, if nothing else. Neither did she write the symptoms off as non-existent, which was quite helpful, [laughs] even if she'd come back to me and said, ‘You know, I don't know what's wrong with you’. I would have been quite happy with that because at least she'd made an attempt to try and solve the problem, so to speak, so she was really great. I thought that she was really helpful.

I15: Acupuncture's my biggest godsend. Dr [acupuncturist's name] has taught me a few points and I moxa myself every night, and, if I'm particularly tired, I'll do it twice a day and that's quite fruitful for me.

I24: It's a feeling of relief ... I had a series of acupuncture appointments, [timeframe] and it really seems to have given me a good boost. And it's just the most wonderful feeling.

Acupuncture was one of the few treatments considered beneficial by some of the participants.

The poorly understood status of the CFS diagnosis and questions concerning the veracity of the syndrome also had a “social impact” for the majority of the participants. Social activities were often one of the first aspects of the participants’ worlds to become restricted by their lack of energy.

I14: I thought people would think it would be contagious, which some people still do. They won't touch a glass that I've had. I have to say, ‘I'm not contagious, if that's what you think’, and they go all embarrassed because they actually realise that they look kind of foolish. So I was really embarrassed. I thought people wouldn't understand, I thought people wouldn't want to be my friend. They wouldn't ask me to do things. Just that lack of understanding.

In contrast, several of the participants commented that the judgement-free companionship that their “animals” offered buoyed their energy and reduced the isolation created by the illness.

Resonant with the illness experience as unbounded and unpredictable, almost without exception, the participants reported having very little “control” over the amount of energy available to them or the affects of the illness more generally.

I28: You take a lot of your abilities as a young person for granted and suddenly, if you don't have that control over yourself, if you can't hold onto what was just said to you, it really challenges your idea of your invulnerability. I couldn't seem to do anything to stop the diarrhoea. I developed ulcerous sores on my belly button and I had this sense that my body was unravelling itself from where it had been so tied into place. Everything was just coming to bits and decaying and there was nothing I could do to stop it or understand it. Not least of all, because of the lack of firm knowledge about the illness and ways of dealing with it.

For most participants, “managing” what energy was available to them was a constant process. One participant provided a detailed account of the “cost-benefit analysis” they would consider before undertaking almost any life activity.

I11: Outcomes, that's what's being weighed up, if you like, what's going to give me my maximum outcome, and whether it's worth risking or even utilising an amount of energy in a particular way ... What I'm trying to achieve is the most effective use of my energy and the most effective outcomes from my life ... Something that today is worth the cost for the benefit that I will receive may not be next week ... It's all energy management. The whole thing, in my view, about living with this illness, once you get past all of the specific physical symptoms that you have to deal with and getting through all of the learning to deal with the cognitive difficulties that come up, dealing with the emotional stuff ... accepting what the limitations are, learning to live within it, that is where the crux is and that is all energy management.

The participants, although very rarely, did relate moments that were exceptions to this otherwise constant need to “manage” their energy.

I11: I'm going and doing things, driving, whatever, and I'm not aware of the tiredness, or the energy levels, or the aches and pains, or anything ... I just go and do things.

These moments offered them glimpses of what they desired: to be “normal”. The following comment presents a common understanding of what normal comes to imply for the participants.

I3: What is it to be normal? It's to have money in the bank and the energy to do things.

The energy isotopy is the most predominant isotopy throughout the participants’ discourse on CFS. This is reflected in the large number of relations between the energy node and cluster (Figure 5) and other nodes and clusters (Figure 14). The energy isotopy is predominantly interoceptive⁵⁹ and proprioceptive although it does involve an exteroceptive dimension. In the participants’ energy narrative, energy functions as the object of value⁶⁰ and lacking energy creates a dysphoric state of disjunction⁶¹ from that object. The ill participants’ energy narrative seems to be based on a categorical axis of lacking (disjunction with) or having (non-disjunction with) energy. Ill participants’ energy narrative contains few examples of contingency (conjunction or non-conjunction). There is more evidence of contingency in the recovered participants’ energy narratives. As an isotopy, energy provides more coherence than any other

⁵⁹ “Interoceptive doing designates actions that are *non-figurative*, that is, actions that take place inside the mind and relate to an internal world, such as thinking, remembering or feeling. The term can be contrasted with that of exteroceptive doing. This designates actions that are concrete and relate to the external physical world such as seeing, eating, jumping etc” (Martin and Ringham 2000, p.76). Cept is a root meaning to grasp and inter is a prefix meaning within, thus interoception is the process of grasping that which lies within.

⁶⁰ “The object – or **object of value** – is then defined as the locus wherein values (or qualifications) are invested and to which the subject is conjoined or from which it is disjoined” (Greimas and Courtés 1979, p.217).

⁶¹ “In narrative semiotics the name disjunction is kept for designating paradigmatically one of the two terms (the other being conjunction) of the category **junction**. This category is defined on the syntagmatic plane as the relation between subject and object, that is, as the function constitutive of utterances of state” (Greimas and Courtés 1979, p.91).

and is central to processes of veridiction⁶² within the participants’ discourse on CFS. Having energy connotes being-able⁶³ to-do, whereas lacking energy connotes not-being-able to-do. Having or lacking energy appears to refer to the participants’ ability to transform with respect to doing⁶⁴.

8.5 “Body” States

In the participants’ discourse on their experience of CFS, the “body” emerges principally through the participants’ talk about energy and, also, through their narrative account of a number of body states, which generally do not have an explicitly expressed relationship to the state of their energy (Figure 6). For all of the participants, these body states interrupt their ability to function in unpredictable and often acute ways, leaving the participants with a sense that their bodies are difficult to understand and negotiate. It is as if a further aspect of the unbounded experience of the illness emerges as a difficulty with sensing their physical needs and limitations.

I5: I lose, and this can be physical as well, I lose my sense of judgement as to when to stop and so, I just keep going because I want to finish that bit a gardening, or I want to finish the book or the crossword or, keep on talking, and where my body is sort of saying, ‘Stop! Stop!

⁶² “The integration of the set of problems concerning truth within the uttered discourse can be interpreted first of all as the inscribing (and the reading) of the marks of veridiction, thanks to which the utterance-discourse shows itself as true or false, lie or secret” (Greimas and Courtés 1979, p.367).

⁶³ “1. In the framework of a theory of modalities, **being-able** (*to do or to be*) can be considered as the name of one of the possible predicates of the modal utterance governing a descriptive utterance of doing or of state. Although it is a concept which cannot be defined, it nonetheless can be interdefined in a chosen and axiomatically postulated system of modal values” (Greimas and Courtés 1979, p.23).

⁶⁴ “The distinction that we have established between utterances of **doing** and utterances of state, even if it refers intuitively to the dichotomy change/permanence, is an *a priori* and arbitrary formulation, which permits the construction of a surface narrative syntax. As the predicate-function of such an utterance, doing is to be considered, in an anthropomorphic syntactic language, as the conversion of the transformation relation. 2. The modal character of doing needs to be recognized. According to our definition – which seems to us to be the least restrictive – a modality is a predicate governing and modifying another predicate (or an utterance which has as object-actant another predicate). In this perspective, any case of doing – whether it be a case of an instrumental doing (causing-to-be), or a manipulative doing (causings-to-do), of a doing which constructs, transforms, and destroys things, or of a factitive doing which manipulates beings-appears as the predicate-function of a modal utterance governing another utterance. 3. Along the two dimensions of narrativity (and of the activities that it is supposed to describe and organize), the pragmatic dimension and the cognitive dimension, two sorts of doing will be distinguished: **pragmatic doing** and **cognitive doing**. This opposition, which at first appears to be self-evident, is nonetheless not syntactic in nature and asserts itself only at more superficial levels of language. Thus, pragmatic doing seems to be distinguished from cognitive doing by the somatic and gestual nature of its signifier, and also by the nature of the semantic investments that the objects concerned by the doing receive (the objects of pragmatic doing being descriptive values, cultural values, in a word, non-modal values). However, the somatic or gestual signifier is sometimes placed at the service of cognitive activities (in the communication or construction of objects, for example). Thus, it is G. Dumézil’s third function which best describes pragmatic doing. 4. The distinction, in the cognitive dimension, between **narrative doing** and **communicative doing** is syntactic in nature. Communicative doing is a “causing-to-know”, that is, a doing which has cognition as the object of value that it aims to bring into conjunction with the receiver. When the axis of communication has thus been recognized, it is then possible to introduce new distinctions – the proliferation of which must not exceed the real needs of the analysis – founded on semantico-syntactic criteria. Thus, first of all, an **informative doing** will be recognized, defined by the absence of any modalization, as the communication of the object of cognition in its (theoretically) pure state. The informative doing can then be viewed as the articulation of an **emissive doing** and a **receptive doing**. The latter can be either **active** (listening, looking-at) or **passive** (hearing, seeing). It is along the same axis of communication that the distinction – which seems to us fundamental for a typology of discourse – between **persuasive doing** and **interpretive doing** appears, thanks to the modalizations and complexifications of the programs of doing which are its results. 5. Narrative doing – which corresponds, in our view, with what could improperly be designated as a “syntagmatic understanding” – constitutes a vast and open field for analysis and reflection, whose importance, through its relations with cognitive psychology, can only increase. Preliminary studies, in the area of discourse concerning scientific topics, have led to a distinction between a **taxonomic doing** (with its **comparative** and **taxonomic** aspects) and a **programming doing**” (Greimas and Courtés 1979, pp.93-94).

Stop!', I'm saying, 'Yes but I just want to do this now, because tomorrow I might not be any good and it won't get done anyway', or, I'm really enjoying what I'm doing'. I don't listen to my body very well like that, so that's why I've been sick so long.

Along with managing their energy, listening to their bodies becomes a relationship that they need to negotiate. For some participants, this is “empowering” and appears to be key to the process of recovery. For others, the connection between recovery and their relationship with their body is less clear, despite the fact that it continues to play a significant role in their explanations of how they envisage recovery. These issues are discussed in more detail in sections 8.11 and 8.12.

One of the most common body states the participants describe is some form of “immune system breakdown”. This “breakdown” of the participants’ immune systems leaves them “vulnerable” to “viruses” and “infections”.

I14: I still have the belief that there is something wrong with the immune system ... that it is an immune system thing, that something has come in, I've been told, whether it's a virus, whether it's a bacteria, I don't understand. It's still in the system and it's still floating around in there. You can't spit it out and every flu, and everything else that comes on top of it just hits you twice as badly.

Several of the participants described an “allergy state” in which they develop “intolerances” to “pesticides” and “sprays” as well as more everyday substances and situations.

I10: Some perfumes I'm allergic to, I can't stand perfumes ... When I go into a shop that's selling Asian clothing or something like that and they're burning joss sticks or something, I'm sneezing within ten seconds and have to walk out ... I notice that I'm allergic to a sudden change in temperature ... If I move into, maybe everybody is, I don't know, but if I move from a warm area to cold, it's okay when I go outside, interestingly, but there are some times I notice my sinuses just start acting up ... I think I'm allergic to things in the soil, like, I find washing potatoes that have got soil on them, I start sneezing Never had any allergies before. I went and had some allergy tests and what showed up were apples and grasses and so spring is really bad and tree pollen.

This “vulnerability” to allergies was most pronounced in the participant with a co-morbidity of CFS and environmental illness or multiple chemical sensitivities.

Many of the participants also described a body state in which their “digestive system” “breaks down”. Symptoms of this digestive system breakdown included diarrhoea, constipation, the passing of undigested food and a process of progressively developing “food intolerances” and “allergies”.

I18: I was found to have food allergies. I literally had to buy a diabetic blood-sugar kit, and I would take my blood-sugar levels before I ate something, and then I would eat something, and take my blood-sugar levels afterwards. Invariably, it would tell me whether I had had a reaction to the food.

A number of the participants reported developing “hypoglycaemia”.

I14: I'd have a hypoglycaemic low and you're craving any sort of food. And that's why you have to be really organised, and sometimes I'm too tired the night before to organise myself.

Several participants reported struggling with incontinence whilst others reported a constant strong “thirst”.

I15: I am incontinent and I have a bladder weakness.

I1: Thirst is one of the symptoms and I seem to spend my life pouring in one end and out the other. This is purified water by the way, nothing more interesting

Fluid retention was also common and the participants related “changes” in their “bodyweight” involving both losing and gaining “weight”.

I10: I developed a way of swinging my legs out onto the floor; and sitting for a while; and then forcing myself to stand; and then forcing myself to take steps forward. Because of the fluid retention, the ankles don't move, so you're like an old person walking like flat-footed.

I8: I lost a lot of weight. I was right down to under seven stone. Hell of a way to lose weight.

I11: Since I've had the CFS the more healthily I eat ... it seems, the more weight I gain.

Excessive sweating caused several of the participants considerable “distress”.

I9: That was shocking. The perspiration would just absolutely pour off me. It would just run down my face, my chest, my back, soaking wet.

In some cases this perspiration was accompanied by “heart palpitations” but in most cases heart palpitations were experienced independently or in conjunction with panic and anxiety.

I9: I had these great palpitations and your heart would palpitate at the same time ... just a fraction of a second later your ears would go, the heart beats weren't even. They weren't even, you'd get this extra large one, palpitation, that's when it affected your ears. And then your ears would just feel all fuzzy momentarily.

Several participants reported regularly becoming “nauseous”, “light headed” and “dizzy”. Some participants reported becoming “clumsy” and “having trouble” with maintaining “balance”.

I12: I'm very clumsy, I walk into anything. Like, I broke my toe and the next week I broke my next toe, doing exactly the same thing. I always walk into doors and into tables and my balance is very, very bad.

Several participants commented that their experience of CFS had an adverse impact on their sexuality.

I11: I don't have the energy to have sex as often as I'd like to.

Many of the participants commented that both their body states and their energy states were responsive to “stress”. The participants reported that, when there was an acute stress in their lives, their symptoms would become more intense.

I13: I had a huge fight with my husband and I just got stressed to the max and it just brought on all the symptoms. The headaches were really bad, I couldn't sleep. I mean, it's another

thing, a lot of people think ME is fatigue, but it can also go the other way and become insomnia. I couldn't sleep, all the aches and pains came back.

Rather than interoceptive or exteroceptive, the participants' body narrative is proprioceptive. All of the body states expressed by the participants are associated with dysphoria and represent a disjunction with normality as the object of value. Although the participants' narrative of these body states does not include direct reference to the state of their energy, in their descriptions, the participants comment that these body states occur less when they have more energy. The body states discussed above were described consistently across all the participant subgroups with the exception of the "allergy" state. This state was described considerably more by participants from the Wellington region, particularly those involved with the Wellington ME Support Group, and those who had been treated by a general practitioner who specialises in treating CFS and is resident in the Wellington area. These participants' tendency to see allergy as an explanation for their symptoms may be related to the explanations for the illness that they met through the support group and the care they received from this general practitioner. In reference to this allergy state, participants from the Wellington region placed more emphasis on allergic reactions as a body response to poisoning. Wellington participants also described digestive system breakdown in more detail. Excessive sweating was reported by both younger and older participants. Although many of these body states are associated with other disorders generally, the participants claimed they could distinguish between the impact of their CFS and "other health conditions", including comorbidities such as depression, anxiety and multiple chemical sensitivities.

8.6 Interacting with Biomedicine

The energy and body states discussed in sections 8.4 and 8.5 are described by almost all participants as experiences that "happen to" them. The participants express needing to describe these experiences as "symptoms" when they attempt to communicate with general practitioners and biomedical specialists (Figure 7). Both consciously and unconsciously, numerous participants draw on the discourses of these disciplines to communicate their experiences in "legitimate" terms.

Many of the participants sought the "help" and "advice" of biomedical practitioners for several reasons. Initially, almost all sought a "diagnosis" and a "solution" or resolution to their illness, often hoping for a "magic pill" or "cure". These participants quickly pointed out that, in their experience, even where a diagnosis was made, no such "solution" existed.

I9: There was no miracle cure. You were clutching at straws and looking for a miracle cure, or looking for something that you were going to take, you could swallow, and just make you feel better, but there was just nothing.

In response to this lack of solution, various participants expressed disappointment and most participants expressed deciding to “nut it out” for themselves.

I8: With ME, everybody's different. They can't sit you down, and say: ‘right, we've got this magic pill, that is going to say arise, and walk, and you're going to feel fine.’ You've got to nut it out for yourself: when you're feeling better, why are you feeling better, what happened that made you feel like this, where is it coming from? Are you best to exercise and get a bit of energy that way or does exercise nearly kill you.

This need to “nut it out for yourself” led many of the participants into a process of “trying to make sense” of the illness (section 8.8).

With the exception of some general practitioners who specialise in treating CFS and the participants’ interactions with neurologists and rheumatologists (see section 8.4), the majority of the participants reported feeling “silenced” and “delegitimised” in their attempts to consult with biomedical practitioners and establish treatment for their illness.

I3: Oh, it's horrible, it's demeaning, you know, you might be washed out and you're saying, ‘Hey, I'm a really positive, highly motivated person.’ [laugh] Believe me. I mean you get treated as though you're quite neurotic.

Given that many of the participants sought “legitimation” and acknowledgment of their experience from biomedical practitioners, this “silencing” accentuated their sense of isolation.

Some participants felt that these “delegitimising” experiences were expressions of a more general “oppression” of “women” and, consequently, felt the treatment and advice they were receiving was “gendered”.

I10: My GP, by the way, in [place], when I told him how I was feeling and I said I'm exhausted by ten o'clock in the morning, he said, ‘Aren't we all’. [pause] And this is typical of the dismissive comments I used to get, an incredible remark, really, for a doctor to make ... He just made assumptions about women.

Several participants described feeling “exposed” by their experience of consulting biomedical practitioners.

I26: I mean, that's quite a thing, going to see different practitioners all the time, and sort of having to expose yourself, expose your symptoms again, what it's like for you.

These participants described feeling most vulnerable when their mental or cognitive difficulties compromised their ability to “comprehend” and “communicate” clearly.

The participants consistently asserted that their CFS was not a form of depression.

I2: I had to describe the symptoms and that kind of thing and had to spend a lot of time accentuating the fact that I wasn't depressed. I have had to the whole way through, really,

because, it's just amazing, I think, there always seems, to me, to have been a real inclination to just slap that tag on you if you'd let them and I wasn't prepared to do that. I honestly don't believe I'm depressed and I have, through the insurance company, I've had to see a psychologist and she's backed that up. I didn't want that, kind of, slapped on me.

Almost all participants claimed that they do not experience the consistently low mood characteristic of depression and, for this reason, many actively resisted “antidepressant medication” whilst those who did try a course of antidepressant medication commented that it was not beneficial in the treatment of their CFS.

I13: One doctor wanted to put me on antidepressants. No way, I just didn't want to go on antidepressants. He talked me into it in a weak moment and I became a complete zombie.

Many participants expressed that receiving a diagnosis of depression was a means to reduce their experience of CFS to an issue of the psyche alone.

Several participants expressed being concerned to receive a “clear justification” for any “medications” they received from any kind of practitioner. Many participants reported experiencing an “unusual” “sensitivity” to medication generally.

I13: I always have the lowest dose possible, and even if it's say, 25 milligrams, she goes, ‘cut it in half’.

A number of participants expressed similar concerns with regards to “exercise”. These participants did not consider that they had received a clear justification, “process” or “guidelines” for the reintroduction of exercise into their lives. Despite their desire to be more active, the participants commented that reintroducing exercise inappropriately often made their condition worse.

I22: Frustrating, when I think of some of the advice now, very annoying, too. I actually started an exercise programme, which really made me very much worse, on the doctor's advice, because she said you're just seizing up, you're not getting enough exercise. I was going for walks, doing all sorts of things and, of course, then I became very much worse.

The participants’ narrative with respect to biomedicine is more thymic⁶⁵ than pragmatic. Considerable dysphoria with respect to biomedicine was expressed consistently and with considerable certainty across all the participant subgroups. The participants’ narratives suggest that the effects of negatively appraised experiences in seeking biomedical care persist beyond recovery. These effects include a reluctance to consult biomedical practitioners for any future health issues and a deliberate avoidance of mentioning having received a diagnosis of CFS. In a very small number of exceptional cases, participants described a well established relationship with their general practitioner. Within such a relationship, whether a diagnosis was established or

⁶⁵ “Situated on the deep level of an utterance, the thymic category relates to the world of feeling and of emotions. It spans the notion made up by the two poles euphoria versus dysphoria and forms the basis of positive/negative evaluation. In other words it gives rise to an axiological system – a characteristic of all discourse” (Martin and Ringham 2000, p.134).

not, treatment options were discussed openly and participants described contributing to the decision making process with respect to their care.

8.7 “Searching” for “Solutions”

Just as many participants requested a clear justification for the use of exercise or medication in their treatment, most of the participants wanted “clear communication” from their general practitioners with respect to their purpose for referring them to “counsellors”, “psychologists” and “psychiatrists”. When participants received an adequate justification for such a referral, they often followed this through. In cases where the relationship between the participant and their counsellor, psychologist or psychiatrist was amicable, several participants reported perceiving that they received considerable benefit from these sessions. Participants reported “gaining” “coping skills” and a “perspective” on the experience of CFS. Several chose to see a counsellor of their own accord and one participant summarised the benefits of this relationship as follows:

I28: The thing was, I just became so very lost about what was happening to me and felt that going to see the counsellor, in a sense, was regaining some form of control. I was attempting to work out what was happening to me in those sessions. As much as anything, I was using the sessions to deal with trauma the doctors had caused me and the whole cycle of ups and downs brought on by the misdiagnoses as opposed to anything that had been pre-existing. Just all the circumstances of the disease are very, very hard.

Where the purpose for these referrals was not clear the participants often felt “disrespected”.

I3: I was shunted back and forth to a psychologist by the GP I was with. It was Dr [general practitioners name], [psychologists name], and he kept saying, ‘Get back to the doctor’, you know, ‘You need more testing, you don’t need me’ and then the doctor would say, ‘I want you to go back to the psychologist’.

Several participants expressed “resisting” seeing a psychologist because they believed that this referral was being offered as an alternative to “addressing” the “physical reality” of their experience.

Apart from the neurologist and rheumatologist mentioned in section 8.4, the participants had also been referred to an endocrinologist, an occupational therapist and several physiotherapists. One participant had received home-nurse help and another had consulted her church minister. Participants chose to consult an aromatherapist, several ayurvedic practitioners, a chiropractor, a colour therapist, several cranial osteopaths, a medical herbalist, several homeopaths, an iridologist, a kinaestheologist, several massage therapists, several naturopaths and a spiritual growth director. Participants had also independently chosen to try a magnetic therapy and various forms of supplementation.

When many of the participants found that biomedicine left them with “little explanation” for their illness and offered “very limited” “help”, they became engaged in a process of

“searching for solutions” from both biomedical and ‘alternative’ health practitioners and forms of therapy (Figure 8). This “search” became very involved for some participants who nonetheless felt that they were “clutching at straws”.

I9: You're clutching at straws basically, hoping that somebody can help. I couldn't. I gave up. Once I went back to work, I just thought, ‘There's only one way to go about it and that's just to keep on going.’

Many participants describe feeling “hopeless” and “helpless” and eventually “giving up”. In this search for a solution from both biomedical and ‘alternative’ practitioners, the participants express feeling vulnerable and occasionally “exploited”, particularly “financially”.

Central to almost all of the participants’ narratives concerning searching for a solution was a process of comparing different health practitioners. This process was underpinned by an axis of opposition between “alternative health practitioners” and biomedical practitioners. When many of the participants compared their experience of consulting “alternative practitioners” to their experience of consulting their general practitioner, for instance, the participants commented that they felt “safer” with the former. The participants made a distinction between the practitioners that “came from” the perspective of “treating illness” and those who were concerned to “promote health”. The participants suggested that the alternative practitioners’ focus on promoting health was a more viable approach to treating CFS.

I2: I'm more inclined towards the natural therapies with ME because, basically, there are no medical ones and because I think the medical people will do damage while they experiment on you, basically. That's the way I felt with the antidepressants and things and I think that's a really dangerous place to be. I don't think the naturopath can do any harm and I think they have actually done me some good. I think even a healthy person can go to a naturopath and they will have the view of keeping a person healthy, rather than the GP who will just treat someone who's sick. They are looking at illness, whereas, I think a naturopath and homeopath are looking at maintaining health, as opposed to treating illness.

Of equal importance to whether a practitioner could offer a solution, and regardless of what therapy a practitioner offered, many participants expressed that the most important quality of the practitioner was their ability to communicate to the participant that they had listened to their concerns.

I22: These are people. Whatever their methods, they listen. They listen and take you seriously and try to find what will help you. They do have open minds about things so, in that way, even though I thought that the homeopathy didn't necessarily work, nevertheless this was someone who did listen and try to understand the problem and also looked at the whole person, the holistic view, and that's important.

Most participants commented that the alternative health practitioners were more likely to listen. The participants considered that alternative therapists provided more adequate “feedback” and were considered more “honest”.

I28: She provides me with feedback. She tells me honestly what her response is to what I'm saying, instead of what I experienced with Dr [name], which was a lot of unpleasant innuendo some of the time. She's very honest about what she thinks in relation to what I tell her and she's obviously telling me what first comes into her mind. She's not trying to present or manipulate or 'doctor' what she's saying in any way, and I use that word deliberately.

Several participants commented that “practitioners” could “improve” the services they offered to those with CFS by “listening” more, being more “honest” and by working more collaboratively with participants and other practitioners.

I2: I think they could all try and work together a bit more, be more co-ordinated in their approach. You could have a centre where they had doctors and naturopaths and homeopaths. If one would be willing to say, ‘I can't help you but maybe this person can’, if they could work together a bit more that would be really good. Because at the moment, they're all working a bit in isolation and I think it would be really good if doctors could just say they didn't know instead of just trying stuff. I think they could give you more information on some of the things they propose doing.

Several participants commented that when their mobility was significantly impaired, they found almost all health practitioners “inaccessible”.

Many participants sought consistency in their care and described wanting to see treatments progressing “systematically”. Many participants describe consistently struggling for continuity in care against a “lack of treatment process” and within the context of an unpredictable and unbounded illness experience.

The participants’ searching for solutions narrative is very distinctively pragmatic and reflects uncertainty with respect to the object of value: a solution. The solution the participants seek is not necessarily a cure. Equally important is the need for the participants to feel heard and facilitated. The searching for solutions narrative is presented consistently across all the participant subgroups. Although a small number of recovered participants suggested what they believed had allowed them to recover, they also described the process of searching for solutions in the same terms as those who had not recovered and with the same degree of uncertainty.

8.8 Making Sense

The participants spoke about trying to “make sense” of their illness experience, to find meaning in this experience and the impact of the syndrome on their lives (Figure 9). Without exception, the participants went to considerable effort to research CFS, “reading” self-help literature, medical literature and engaging with the representation of the illness in the media. From the self-help literature, much of which is written by former sufferers, the participants gained a sense of “validation” and solidarity. They also scoured this literature for “coping strategies”.

I2: This one [book] is about more practical things, which you figure out yourself anyway. This one [book] is more to do with the mental aspects, which I found really good because the

practical things are obvious, but, to have a book that validates what you're going through is more valuable because, I guess, you don't really understand what you're going through.

The participants drew on the material they read, advice they received from ME Support Groups, and the explanations given by the practitioners they consulted in their explanations of how their illness had eventuated and what perpetuated it.

The most common way the participants made sense of their illness was through a narrative of “immune system breakdown”. Many participants perceived an external “agent” or internal infection to be responsible for “compromising” their immune system’s ability to “stay balanced” and “defend” them. The most common compromising agents mentioned were *Candida albicans* and glandular fever (Epstein-Barr virus).

I20: The immune system is always on the edge of collapse. Mine is very impaired and I have a theory, based on my own experience. I have very bad *Candida* because the immune system cannot keep the *Candida* in check. If I eat something that I'm not used to, something that will feed the *Candida*; I have the immune system come in to try to check it, well, first of all the *Candida* will take over, it will start an on rush and the immune system will come in, try to check it, and then you will be back into a total fatigue again. So that is the whole thing in a nutshell.

Although the participants see glandular fever as a common initiator, they also make a clear distinction between their experience of glandular fever and their experience of CFS.

I18: With glandular fever, I could sleep all day. I didn't feel well, I'd be in bed and that's why I slept. There was a tiredness and there was a fatigue, but, it was different. With this [CFS], I don't sleep. I'm really, really tired and my body is hurting and I've got no energy but I can't sleep. I can lie in bed all day and have a good rest but not sleep, whereas with glandular fever, I'd be out for hours, I'd sleep twelve hours at night and then I'd sleep three hours, four hours in the afternoon. It's like this sleeping disease. This [CFS] is not like that, the sleep is not a deep slumber, it's not a quality sleep and the other one is. With glandular fever, I was aching all, here, but quite often it felt like it was under here, whereas with this [CFS] it's very definitely more up here.

BH: It [glandular fever] felt like it was more under your chin and this feels more like, under your ears?

I18: Yes, very definitely and the aches and pains were different. The aches and pains with ME stay for much longer and they bother me a lot more. It's a funny way of putting it but [the aches and pains are] more noticeable, I guess, much more noticeable than with glandular fever.

Many of the participants made sense of their CFS in terms of food allergies or food intolerances.

I8: If I had a bad day, I had to try and work out what it was that I'd done, or what it was that I'd eaten, that had caused me to have a bad day, especially if I'd had two, or three good days. So, I would have to go to my diary and have a look and see what it was that I could possibly pin-point. It was normally a food. If I suspected a food, then I would wait until I came right again and then eat that food and see whether it affected me again. It was a process of elimination and it was a very costly exercise. I ate some pretty foul things in trying to find foods that I could eat.

Several of the participants made sense of their CFS through a concept of “chemical sensitivity” or “chemical intolerance”. Participants named substances, exposure to which they suspected had caused a “gradual poisoning”, which they considered to be the cause of their CFS.

I26: Some people with chronic fatigue often do react to building materials, or carpets and things like that. Chemicals show up, it's one of my causal agents. Two examples: a few years ago I was working on the gate out there, which is made of ground-treated pilings. I was hammer, hammer, saw, saw, I felt fantastic in the morning and then, in the afternoon, I started feeling really achy and really tired and quite headachy and it was, sort of, was quite immediate. It wasn't like I got tired from the work, it was more that I'd reacted to something and when I thought about it, I'd been sawing this ground-treated stuff and probably breathing it in.

This explanation was considerably more prevalent amongst the Wellington participants, particularly members of the Wellington support group and those who had consulted a GP who specialised in treating CFS.

A small number of participants made sense of the onset of their CFS through what they described as the “ME persons’ nature”. This “very gentle”, “placid” “nature” was “perfectionistic” and a “type A”, “driven”, “high achiever” and predisposed “the person” to CFS.

To make sense of CFS participants often drew upon several of the explanations above.

I18: A combination of having a lowered immune system through glandular fever and this really stressful event and, perhaps, if I'm honest, a little bit about my personality, because I tend to be a perfectionist and I tend to push myself too hard anyway. So I think all three.

A means by which the participants tried to resolve the differences and contradictions in the explanations offered by others and the material they read was to perceive the illness as “idiosyncratic” and “very individual”.

I11: Another thing about CFS is it's very highly idiosyncratic. Each person who has it will have a slightly different cluster of symptoms and will be affected by different medications, different foods, different chemicals in the environment. Must make the researchers nuts.

Seeking definition for the illness in the form of a diagnosis and making sense of this diagnosis were very significant aspects of the participants making sense process. Some of the participants described themselves as “self diagnosed” as they were unable to find a practitioner with knowledge of CFS. Most of the participants were diagnosed by a general practitioner. A small number had received a CFS diagnosis from an alternative health practitioner or from a psychiatrist. The process of finding a practitioner who listened, investigated numerous possible diagnoses and eventually reached a diagnosis of CFS was often time and energy “consuming” and “emotionally draining”.

I1: In the early days, I went, I think nearly everybody does, went around trying to find what was wrong with me, what would help. There came a stage when I was too ill to do that anymore.

For some participants, receiving a diagnosis held very little significance or was even “disappointing”.

BH: How did you feel when you came to a diagnosis?

I2: Oh, nothing. It wasn't really any different. It was like, ‘Great, now I can tell people I've got something that no one's heard of, [laughs] that no one really knows what it is and for which there is no test and no cure’. It wasn't any great milestone, not psychologically, and certainly not in terms of treatment or anything like that.

Most of the participants, however, felt receiving a diagnosis was of considerable “significance”, Participants expressed considerable “relief” at having an “identity” and a “name” for their experience. This ability to give “it” a name enabled them to “communicate” more effectively with others.

I5: Hugely relieved. It had a name. I wasn't going mad; it wasn't all in my head. I wasn't just imagining it all. It was a huge relief even though it was sort of controversial at the time. It was a huge relief to know that it had a name because some of the symptoms at that time were really pretty bizarre.

Several participants saw the diagnosis as a foundation from which they could start to “care” for or “help” themselves.

I14: That's really important for a sufferer to get some sort of diagnosis. It's like, ‘God, now I can actually start helping myself, or looking to help myself.’

Despite the controversial nature of the diagnosis, several of the participants expressed that having a diagnosis made their experience more “acceptable” to others.

I15: I think in our society we have been conditioned, ‘It's not okay to have an illness’, like Florence Nightingale, who supposedly had ME. She was just totally accepted, wasn't she? She was sick. But in this day and age, if you just said to your society that you're sick, you don't know what's wrong with you, are you really accepted? Or are you some strange out of space character?

In contrast to the pragmatism of searching for a solution, the making sense isotopy is principally cognitive⁶⁶ and interoceptive. It represents the participants’ attempts to understand the veracity of their experience for themselves. In a sense similar to the stages isotopy the making sense isotopy conveys a search for certainty, a believing to be. Although the making sense isotopy is expressed by all of the participants, it is least prevalent amongst the recovered participants and most prevalent amongst those participants who had been ill for more than six

⁶⁶ “1. The adjective **cognitive** is used, in semiotics, as a specifying term by reference to various forms of articulation of knowing – production, manipulation, organization, reception, assumption, etc. 2. Hierarchically superior to the pragmatic dimension which acts as its internal referent, the **cognitive dimension** of the discourse is developed in parallel fashion with the increase in knowing as a cognitive activity attributed to the subjects installed in the discourse. If the pragmatic dimension – along with the sequence of programmed actions proper to it – does not necessarily imply the cognitive dimension, the reciprocal is not true: the cognitive dimension, which can be defined as the taking in charge, by knowing, of pragmatic actions, presupposes them” (Greimas and Courtés 1979, p.32).

months at the time of the interviews. Some of the recovered participants expressed a reluctance to recount how they had tried to make sense of their illness.

8.9 “Other People”

The majority of participants expressed considerable concern with respect to “other people’s” reactions to their illness and how these reactions shaped other people’s responses to them personally (Figure 10). Many participants commented that “others” were inclined to consider them “hypochondriacal”, “neurotic” and “lazy” and the “controversial” nature of the diagnosis contributed to this. These reactions left participants concerned that the veracity of their illness experience was being brought into question. For some of those participants who experienced the syndrome as all consuming, this “questioning” of their experience amounted to a questioning of their entire, already “shaky”, “world”.

I30: Something that has affected me quite a bit is what others think of you. I was always out there as a vibrant and positive person and then, all of a sudden, I disappear off the face of the earth, especially to the clients and my staff. Things like that. ... I feel like some people think I've had a nervous breakdown. People don't understand your illness. They think you've gone loopy and that it is all in the head and things like that. That has been quite difficult to work through.

Participants described three ways in which others did not “understand” or “appreciate” their illness experience. Firstly, “friends”, “work colleagues”, “neighbours” and “family members” often did not appreciate the “extent” of the illness.

I14: From my experience, the only thing I've found is that people think you're perfectly normal, that you can do anything anybody else can. The only thing is you get tired.

Secondly, many participants observed that others found the unbounded and unpredictable nature of the illness difficult to “accept” as “real”.

I18: That's really important ... people having some understanding of the illness. The biggest thing is why I can do things some days and not others ... For example, at work, what people think is, ‘What's going on here?’ One day I can [do] an eight or nine hour day, then another day, I can't get out of bed. I don't know. How do you get people to understand that sort of thing and, really, why should they? I mean, there are so many illnesses and things in the world. ... I'm gently trying to tell people a few things about it as I go, but you have got to be careful not to talk about it too much.

Lastly, participants noted that others’ perceptions of their illness were often coloured by others’ “own past experiences”. In a few cases, these past experiences facilitated others’ understanding. More commonly, the participants expressed that others’ assumptions drawn from past experience were a “hindrance”, adding layers to others’ perceptions which the participants then needed to negotiate.

I28: I think they have to employ a suspension of disbelief, if they're going to be helpful to somebody that they care about. They have to employ a suspension of disbelief. I think listening and not imposing your own experiences is really important because, if it's outside your experiences, your experiences aren't particularly relevant. What I had, a lot of the time, was people trying to understand what was happening to me, by relating it to something that happened to them that wasn't particularly appropriate and it just confounded the situation somewhat more. I'd recommend just trying to get a picture of the sufferer's, or survivor's, experiences without imposing what's happened to you on that.

The most common “reaction” from others the participants described was “denial”. This was most common with “family members” and was also the most difficult reaction to negotiate.

I28: There was this attitude that if they made me behave like things were normal, things would be normal. I'd be completely dead on my feet and in physical agony because they were making me do activity. I'd be just wanting to go to bed and they'd say no, let's go off and do this or let's go off and do that. And they were obviously pushing themselves to great lengths, too, and tiring themselves emotionally and physically to try and put me in a position where I had to behave like things were normal and they weren't. It took them an awfully long time to even begin to accept that it was real, and it wasn't a figment of my imagination or something I took myself into. So often mum said ‘I just wonder if you're not talking yourself into this’.

Many participants found this denial isolating. The only response participants considered was available to them in the face of denial was to “withdraw” from spending time with family. In some cases, they also “withdrew” socially. Equally, the participants observed others “withdrawing” from spending time around them, particularly “friends” and “workmates”.

I28: There were different reactions. Some friends just left me alone all of a sudden. I guess, in a way, that's how I found out who my friends really were. It surprised me, who stuck around and was really supportive, and really patient when I couldn't remember what they were saying to me all the time, and who didn't.

Several participants described a number of “coping strategies” they employed to “cope” with others. These participants described deciding not to “commit” to “attending” events with others whom they considered did not understand their illness. Instead, they chose to “spend time” with those who did understand and accept their limitations. When they were with such a person, the participants described feeling “safe” and “protected”.

I30: I would only go out if I felt safe and protected by the people I was with. I needed to be in an environment where, if I felt ill, I could go home and it would be under my control, rather than an environment that I felt that, hey, I can't get out of here and go home. Then it was not so good.

BH: How did you go about making sure that you felt safe and protected?

I30: Made sure that my family and friends were aware of what the situation was, and that it was no reflection on them, if we went somewhere, and I had to turn around and say, ‘Go’. Not that that happened very often but I needed to voice those concerns.

BH: Make people aware?

I30: Definitely.

BH: Can you give me an example of when it did happen?

I30: Yes I can. I went to the opening of the pier and was out there with all those people, the hot bright sun, cued up, feeling a bit apprehensive about going up this structure that didn't

look very safe. I don't know if you saw the steps, but it was just scaffolding. Man, it was shaking. I got up on the pier and I felt like I was out a control. There's all these people pushing and shoving and there was a queue, too, forming to go back down. I thought, ‘Oh my god, what if I've got to get out of here?’ I said to my friend, ‘I've got to go’, and she said, ‘Okay, that's fine’ and away we went.

In situations where others questioned the participants’ “sanity”, or for some other reason the participants did not feel accepted but nonetheless needed to function, rather than confront this lack of acceptance directly and potentially face being labelled insane, the participants described “hiding” the state of their health by “putting a mask on”. Many participants stressed that they “put a mask on” out of necessity.

I10: It's like going around with a mask on all the time. I used to mask these symptoms constantly. Psychologically, it's a really bad thing to go around with a mask on and I hadn't done that before. Well, I'd done it a bit, of course, but nowhere near to that extent. I didn't like it. I didn't like myself for doing it. I would say that that [was] my way of coping. Not only did the illness lower my self-esteem but the ways of coping did as well because there was no other way that I could think of. It's a bit like I was lying, a lot of the time, anyway, at least pretending. I suspect a lot of people do that.

Although the participants disliked “wearing a mask”, they do not express resentment towards others for needing to do so. On the contrary, the participants claimed to have “empathy” for others’ lack of understanding of their circumstances. The participants convey the belief that the illness experience has given them “more empathy” for others and a better understanding of the “claims” made by other “minority groups”. This empathy and appreciation of the difficulties of communicating illness changed the participants’ broader view of health.

I25: How do I think about health more generally? Well, I certainly don't take it for granted anymore. I have an appreciation for [what] others are going through with their different states of health. It's not straight forward, it's very nebulous. It's not static, it's ever changing, and you can't judge people by the way they look anymore. So that was quite a revelation. When I got this illness, people would say to me, ‘Oh but you look so well’ and yet you don't feel the way that you look.

Specific relationships with others the participants were cognisant of “negotiating” included relationships with existing and future “employers” and “general practitioners” as well as relationships with their “children” and “spouse”. Some participants conveyed how “flexible” their existing “employer” had been when they had first become ill. Several described experiencing “discrimination” when applying for future positions, even after they had recovered from CFS. Many described being “inclined” not to mention their health to employers if they were ill and some participants avoided mentioning the fact that they had recovered from CFS.

I25: I think the judgment is, ‘She's got this illness, fatigue syndrome? She looks okay to me’. I don't really want to be labelled as sick. I don't like to be classified as sick. I don't want to be categorized and pigeon-holed into something so that is why I refrain from mentioning that I have this. When I applied for this job, I refused to say that I was sick because I didn't want to

jeopardize my chances of getting a job, so I just didn't say anything. I've managed to cope with it. If I hadn't, I would have stopped doing it anyway, but I thought, 'Well, what's the point in mentioning it? I'll see how I go and, if I can't do it, I won't do it.' You learn to keep things close to your chest, [laughs,] really keep your cards close with regards to your health.

Similarly, many participants chose not to mention their CFS diagnosis to general practitioners when consulting them for assistance with other health issues. Almost all recovered participants chose not to tell subsequent general practitioners of their CFS experience.

Most important to the participants was their spouse. Partners that were described as supportive, accepting and understanding contributed considerably towards the participants' quality of life and this reduced these participants' sense of isolation.

I28: I drew heavily on my partner's support. He was living in [place]. He would come down most weekends and drive me to the beach or somewhere and he took me out to [restaurant] a lot because he knew I enjoyed that and it lifted me, things like that. He was really good about spending a lot of time in bed with me, just cuddling, holding me, giving me human contact. That really, really, really helped. I got real nourishment from that intimacy. That was brilliant.

For most participants, however, the “strain” of “coping” with the illness coupled with a lack of understanding led to relationships “breaking down”.

I30: He rang the other day and he said something like ‘Oh, you've still got that then’. That sums up where he's at, never tried to understand how I was feeling. He just thinks I've got the flu, had the flu for six months.

Participants with dependent children were acutely aware of the impact of their illness on their ability to “parent” their children and be “available” for them.

I3: Well, I would have had more energy for my kids, been closer to them and done more with them, everything in general. Being able to help them out more, taking my grandson to the movies and all that sort of thing. I just can't do that.

These participants expressed concern that their children may have experienced a lesser “quality of life” than they may have had their parent not been ill. One participant commented that the illness may have adversely affected her “pregnancy”.

Several participants described other people who did understand them. These others listened, were “totally honest” and accepted them “unconditionally”.

I26: I suppose that acceptance is about very much allowing me to be how I am. I think that quite often, with a lot of people, I feel I need to be something for them, whereas it has been very good to have someone who I can just be how I am and if I'm a blob, that's alright.

This “unconditional acceptance” and “honesty” provided the participants, literally, with the “space” to “exist”, to be precisely who they were. In this space, the participants were able to be totally honest. One participant described these dynamics in their relationship with their minister.

BH: What was important about being accepted unconditionally?

I15: You weren't really afraid to be who you are. You could just be and that meant a lot to me. Some ministers are better at doing that than others. I would say that the one we have at the moment is the best at that because of her background. Perhaps, with the others, I would have been more choosy of what I would say. [With her], I can be totally honest and open and she said, likewise, how open I had been. That means she can help you all the more.

ME Support Groups also gave some participants a space where they felt accepted, could be themselves unconditionally and had a sense of “belonging”.

I1: Quite often, I wouldn't stay for the whole meeting. I'd be too tired and I have to drive home, but that's okay. Or conversely, if I wasn't interested in what the guest speaker was talking about, I'd come later and skip that. It was just mingling with people in all stages of the illness and some people have got better and have started work again and others are just finding out what's wrong with them. I just found it a great comfort, as well as somewhere to go, like a group of people I belong to, having belonged nowhere for so long.

Equally, at an appropriate point, “disconnecting” from a support group was for some participants a “powerful step” towards “focusing on wellness”.

I1: Focusing on wellness led eventually to me deciding I didn't want to read about ME. I wasn't interested in medical stuff about it, so I stopped getting it, and I threw my old copies of the [support group] newsletter. I read over them and threw them out with reverence, but I threw them out.

Participants described a small number of occasions where they were able to communicate their needs to others. In these instances, the participants felt supported when others allowed them the “flexibility” during everyday activities to deal with their limitations, including the ability to “lie down” when needed and the ability to “withdraw” from a social situation to take “rest” from “constant interaction” with others. A few of the participants indicated a number of practical areas in which they could benefit from others “support”, including utilising “home help” for “meals” and “housework”.

I3: A couple of meals a week, something like that would just make all the difference. Even though I'm sitting here looking able bodied and everything, by the time dinner comes, it's going to be a different story. Just to have that relief, just to lighten things, just makes such a difference.

The participants' narrative account of other people appears principally exteroceptive and expresses considerable dysphoria despite the empathy the participants claim for the difficulty others face in understanding them. This dysphoria reflects a state of lack and disjunction with the objects of value acceptance, understanding, support, appreciation, flexibility and unconditional being⁶⁷ on behalf of the other. In contradiction⁶⁸ to the participants' desire⁶⁹ or wanting⁷⁰, the

⁶⁷ “Outside of its ordinary use, the lexeme **being** is used, in semiotics, with at least three different meanings: (a) It serves as copula in utterances of state; thus, by predication, it joins to the object properties considered “essential”. On the level of semantic representation, such properties are interpreted as subjective values in junction with the subject of state; (b) It is used as well to name the modal category of veridiction: *being/seeming*; (c) Finally, it designates the positive term of the immanence schema: it is then in a relation of contrariety with seeming” (Greimas and Courtés 1979, p.22).

opponent⁷¹ other is perceived as not-being-able-to-do and not-being-able-to-be. By “denying” and questioning the participants’ sanity, the opponent does not sanction⁷² the participants’ illness state of being as real. Not being able to sanction the participants’ state of illness entails not-being-able-to-be accepting, unconditional, understanding, supportive, appreciative and flexible. This lack of sanction denies the participants the space to be, to exist honestly, without a mask or without having to withdraw. For the participants, the principal issues at stake here are veridiction and the attainment of sanction. Sanction is the principal isotopy that underpins the participants’ narrative with respect to others.

8.10 The “Impact” of CFS

Both participants who were ill at the time of the interviews and, retrospectively, the recovered participants, discussed the “impacts” of CFS on their lives (Figure 11). Many participants described the impact CFS had on their “status”. Most claimed CFS had adversely affected their

⁶⁸ “1. The relation **contradiction** is the relation which exists between two terms of the binary category *assertion/negation*. Since the names ‘relations’, ‘term’, ‘assertion’, and ‘negation’ refer to non-definable concepts, the above definition is located on the deepest and most abstract level of the semiotic network. 2. Contradiction is the relation which is established, as a result of the cognitive act of negation, between two terms of which the previously-posed first one is made absent by this operation while the second term becomes present. Thus it is a relation of presupposition at the level of the posited contents: the presence of the other, and vice-versa. 3. As one of the constitutive relations of the semantic category, contradiction defines the two schemas (s1 - ~s1, s2 - ~s2) of the semiotic square. The terms of the schema are said to be contradictory to each other” (Greimas and Courtés 1979, p.61).

⁶⁹ “1. **Desire** is a psychological term often opposed to will. Properly speaking, it therefore does not belong to semiotic terminology. From the semantic perspective, it can, with fear, constitute a pair of contraries – the category called by R. Blanché *philia/phobia* – in which fear is not a non-wanting but a contrary wanting. On the figurative plane the two terms can be formulated in various ways. Thus, for instance, desire is often expressed by a forward movement (a quest for the object of value) while fear is manifested by a backward movement (running away). 2. Semiotics far from denying the “reality” of desire, views it as one of the lexicalizations of the modality of wanting. Thus semiotic research should involve the development of a logic of wanting (parallel to deontic logic), in which the terms desire and will would designate the variables of wanting, and which would then be correlated with more complex semantic structures” (Greimas and Courtés 1979, p.76).

⁷⁰ “1. **Wanting** is the name chosen to designate one of the predicates of the modal utterance that governs either an utterance of doing or an utterance of state. ... 2. According to the type of utterance it governs, the modal utterance of *wanting* is a constituent of two modal structures that can be designated, for short, as *wanting-to-do* and *wanting-to-be*” (Greimas and Courtés 1979, p.372).

⁷¹ “When the role of negative auxilient is taken up by an actor different from the actor of the subject of doing, it is called **opponent** and corresponds then, from the point of view of the subject of doing, to an individualized *not-being-able-to-do* which, under the form of an autonomous actor, thwarts the realization of the narrative program in question” (Greimas and Courtés 1979, p.220).

⁷² “1. **Sanction** is a figure of discourse, correlative to manipulation, which, when inserted into the narrative schema, occupies a place in both the pragmatic and cognitive dimensions. Inasmuch as sanction is exercised by the final sender, sanction presupposes that this sender has an absolute competence. 2. **Pragmatic sanction** is an epistemic judgment, passed by the judge-Sender, concerning the conformity of the behavior and, more precisely, of the narrative program of the performing subject. It is made with respect to the axiological system (justice, ‘good manners’, aesthetics, etc.), implicit or explicit, such as it was actualized at least in the initial contract. From the point of view of the subject-Receiver, pragmatic sanction corresponds to retribution. As such, it is the result of another function in the structure of exchange: it is the counterpart called for by the performance carried out by the subject conforming to its contractual obligations. This compensation may be positive (recompense) or negative (punishment); in the later case, depending on whether the punishment is given by an individual or social sender, negative retribution is called vengeance or justice. These different types of retribution permit the reestablishment of narrative equilibrium. 3. As a judgment concerning doing, pragmatic sanction is opposed to **cognitive sanction**, which is an epistemic judgment of the being of the subject and, more generally, of the utterances of state that it overdetermines thanks to veridictory and epistemic modalities. (Here could be placed the concept of acceptability, used in generative grammar and presented as an epistemic judgment, comparable to cognitive sanction.) From the point of view of the subject-Receiver, cognitive sanction is equivalent to the recognition of the hero and, negatively, to the foiling of the villain. Recognition on the part of the Sender is the compensation resulting from the glorifying test, taken on by the subject-Receiver. 4. By transposing sanction, viewed as a narrative trajectory, to the level of social semiotic practices, we can foresee the elaboration of a **semiotics of sanction** (correlated to a semiotic of manipulation and a semiotics of action)” (Greimas and Courtés 1979, p.267).

status and some felt that the illness had reduced them to the “lowest of the low”. Few participants considered that CFS had not affected their “standing”.

I23: Profoundly, when I'm sick, it brings shame to the family to some extent. I think my parents would like to have kids that they can boast to their friends [about]. My daughter's done this and my son's done that. To have a sick daughter for a long time, people will look and. I mean it's very judgemental. but I got that impression that I was a failure to them and. in terms of society. I wasn't pulling my weight. I was a burden on the state. I didn't like that. I was raised to contribute, to give, and here I am taking money of other peoples' earnings. Even though it was tax payers' money. I thought I was taking it, therefore my status was lowest of low. No room for an ego, I'll tell you. It's humbling and humiliating and the sense of powerlessness is revolting. Not having the power to control your own life, having to be dependant. Oh, the lesson I had to learn, to ask for help. I had never asked for help and then I had to ask for people just to feed me and I really had to be humbled. In my life, I had to be really, really humbled, and boy I was. My status was no money, taking off other people, like the taxpayers, not the successful daughter your parents want ... I'm just not definable at times.

“In-valid invalids”, “powerless”, “dependent” and “indefinable” is how many participants described themselves. Fundamental to this loss of status is a loss of “independence” and the ability to “contribute”, particularly “financially”. One participant described a connection between the loss of status and “self esteem”.

I28: Lowers your status incredibly. Just going from: being independent to dependent, both in a financial and social sense; from being well and strong, to being weak and ill; from achieving to not achieving; from having measurable achievements to not having anything like that, like grades, things that society recognises, like grades and money. Those are the big ways, massive lowering of status, absolutely. It's part of why the illness is a self-esteem problem.

Loss of status was described consistently across recovered and ill participants. Some recovered participants conveyed that having a history of illness continued to affect their status after recovery.

Many participants described a loss of “confidence” in their ability to participate in the world as one of the impacts of CFS.

I21: My feelings of well-being about myself were based on being physically fit, being out socially, doing things with people, doing a good job at my work, just all those things and so a lot of that fell away. It was like, well, what's left? I lost confidence, social confidence.

This “loss of confidence” most often surfaced in “social situations” and was most acute in relation to the participants “ability” to “work”. Many of the participants who were unwell at the time of the interviews expressed that this loss of confidence would make “re-entering” the “workforce” very difficult. This sense of “alienation” from their work developed quickly. One participant who spoke explicitly about this was interviewed twice within a month of receiving her CFS diagnosis after being ill for approximately six months. Within the time framed by these two interviews, the participant described changing from someone who was confident in a very

demanding vocation to feeling strongly that they may never be able to return to this vocation due to a lack of confidence in their ability to perform.

I19: Heaps changed since I last spoke to you. Before, I'd only been off work about three weeks, when I spoke to you last time. Now, I've been off over two months and it's really affecting my self-image. I'm feeling far more useless and getting to the point where, like, you go, 'I really don't think I can ever go back to work because I just don't have the self-confidence anymore to go back to work.'

This loss of confidence during the duration of the illness is described by both ill and recovered participants.

Almost all ill participants talked at length about the impact of CFS on their “career” as a loss of “opportunity”. In this respect many described the impact of the “ambiguity” created by CFS as the loss of a “clear career path”. Several ill participants were more ambivalent, expressing that they would “not choose” to “return” to their previous career as this career no longer reflected the “change” in their “values”.

I17: My career is totally stuffed. [laughs] Absolutely. I finished Honours, I'd just started working on contract. I was just setting myself up, basically, as a consultant. I'd got a few clients, things were looking as if they were going to happen and that was it. It was over. Absolutely stuffed.

I11: [laughs sarcastically] It [CFS] has caused me to have a mid-life career change. Basically, the [type of career] career's blown out of the water. I've been out of it now too long, partly staying at [workplace], which I'd never intended to do. I was there specifically to pick up work on one project. There was a hole that I had on my CV and I wanted to plug it. Had the opportunity to do that, never intended to stay, and, so, where I had been up until that point, and where I would be able to go back into the workforce now is completely different. However, I also have rethought my ambitions in that respect and have decided that, in fact, that kind of career is no longer a major driver for me.

Some recovered participants considered the loss of their previous vocation problematic because it entailed the need to retrain or re-establish themselves. Although still an impact of CFS, often recovered participants saw this loss of their previous vocation as an opportunity to change to a career that better reflected who they had become after the illness experience.

Almost all of both the recovered and ill participants expressed a sense of loss with respect to “life opportunities”.

I16: I guess a lot of sadness that I was actually like this, that my body was like this, a lot of sadness for all the lost opportunities of life. I mean, there was lot of things I felt like I was missing out on. I had this dream of going overseas and working and travelling and doing all these things and a lot of that went out the window. A lot of sadness about that ... a lot of my identity, of who I was, and my ego stuff I guess, my identity was based around doing things, being physically active, doing my work, seeing things, doing things. So I guess there was a big loss with that, and frustration I couldn't really do any of it.

Recovered participants described not being able to “make up for lost time” or opportunities. Many participants described “grieving” over the loss of status, confidence, independence, career

path “clarity” and life opportunities and the self “identity” that had accompanied these previous opportunities and abilities.

Ill participants expressed grief over losing their identity as a “well person”, despite their resistance to being “labelled sick”. Both the recovered participants’ retrospective account and the ill participants’ contemporaneous account suggest that the CFS symptoms that had the most impact on their sense of identity were the following energy states: closing down, anxiety, panic, agoraphobia, brain fog, memory problems, and difficulties relating to others such as difficulty talking and listening (section 8.4).

Recovered and ill participants describe an experience of invisibility that contributed to this “loss of identity”.

I10: Oh, you're invisible. Invisibility: not being seen, a person ill with chronic fatigue. ... Most people don't notice it. It's just that horrible sense of ‘nobody can see me, nobody wants to know’. I think it's a very, very difficult aspect of the illness. If you have a broken leg, or something that's visible, then people can relate to you as an ill person. Instead, they relate to you as a healthy person. Their expectation is, if you're healthy, you will behave in those ways and you can't do it. You have to try and behave as you feel and they just walk away from you. People walk away from you as if you're a bad smell.

The “invisibility” the participants’ experience and the invisibility of their illness also contributed to their sense of isolation.

Many of the ill participants and recovered participants retrospectively describe an impact of CFS as a difficulty they “faced” in “keeping” their life activities “balanced”.

I14: It's tiring. I said previously about not fighting it, but in some ways you've still got to, there's still got to be an element of fighting it, not to give up. I don't mean fight it black and blue, like I did at the beginning, but you can't give up and think, ‘I can't do this’ and just crawl into a ball. That ongoing thing can be really hard, in terms of keeping your self-esteem up, keeping your confidence, keeping your job, your friends, everything like that. It's hard work.

Keeping balance was “tiring”, “emotionally” and “energetically”. Several participants described the need to “stay balanced” in their “attitude towards” the illness; the need to “negotiate” their “position in relation” to the illness. This is discussed in more detail in section 8.11.

As well as grieving over the loss of status, confidence, independence, career path, life opportunities and identity, all participants described direct emotional impacts of CFS. What the participants are referring to as the emotional impact of CFS is *not* symptoms of CFS that are emotional, rather, they are referring to the impacts of the illness that are emotional. Those characteristics of CFS that had the greatest emotional impact for the majority of the participants were the “multidimensionality” of the energy and body states and the all consuming or all pervasiveness of the illness. These are the aspects of CFS the participants found most difficult to manage. Many described CFS as “emotionally gruelling” because there seemed “no respite”

from the process of constantly “managing symptoms”. As soon as they had “dealt” with one “issue”, “another” would surface.

I14: Soul-destroying. You would feel like you would address one area, I had the dizzy heads, you'd go and address that area, in whatever way you could and then you'd just be back to thinking ‘I'm under control, this is good’, and then the digestive system would give you a bit of a thrill and it would decide that it was going to make you ill. And it was just like every little thing, I had problems with my back, and problems with my neck, and then I got blinding headaches for two weeks, and then I had really bad sinuses and, and, and.

Many recovered and ill participants described “blaming” and “judging” themselves for their illness, feeling “deeply ashamed” and “guilty”. Some participants “accused” themselves of “being lazy”, “malingering” and “not participating” in “life”. Several participants considered these emotional impacts to be symptomatic of “denial”.

I28: If you have a lot of people saying, ‘It's your fault’, eventually you do wonder, you do take it on board. Especially if it's people in authority like the doctors, they will ask you things about your diet and what you've done that sort of imply that, somehow, you brought this on yourself. I was aware that I wasn't having any sort of input into the world around me and I sort of thought that I was fairly worthless, eventually, because of that. I did constantly wonder whether it was my fault that I was sick, whether it was something that I'd done, or whether I really was perhaps talking myself into it somehow. ‘You have to really despise somebody that could do that to themselves’, was what I thought. What a weak coward, not even able to face up to life, to the point where they have to shut their body down and live in a sort of almost death in life situation. I tried very hard not to think that way. Sometimes I did.

I21: I'd be giving myself a hard time. It was like not actually acknowledging what was true for me, what was going on and so then I'd make myself do something and then, I'd feel worse because I'd say, ‘Look, you stupid idiot, you should not have done that because now you feel worse’. And, so, just a continual judging thing that would build up, which was really, detrimental to feeling better.

Two thirds of the participants openly expressed having actively “contemplated suicide”, whilst others had “welcomed the thought of death” as an “escape” from the “never ending living death” of the illness.

I4: At its worst, you just want to commit suicide; you just can't see any point in going on. I guess it's just like depression would be for anyone, you just feel, ‘what's the point’. You're sick of it and you're not going anywhere and it's just happening all over again. And everyone else is out there having a great time and you're not and life is just, sort of, passing you by. I've had a few better times since the relapses. I always focus on that and think, ‘Yes, I've climbed out of it before, I can climb out of it again’, so I don't dwell on it. I try to be positive. Because, of course, being a mother and a wife, you are the pivot of the family, really, the centre of the family so the whole mood of the family is on how you are. So I often try and cover it up quite a lot.

Along with the unboundedness of the syndrome, the undefined chronicity, the “intense pain” and weakness, the numbness, brain fog and memory problems, the participants found “being suicidal” “frightening”. During the most intense periods of illness, however, the participants

claimed that they were “too tired to be frightened”. It was only later that they had the energy to be frightened.

I5: I thought, ‘Now, this is really odd, why am I not frightened?’ I thought, ‘I haven't got the energy to be frightened. That's pretty weird.’

BH: Can you tell me about falling asleep in the shower? [both laugh] What happened?

I5: Well, I can hardly remember. I think it was one of the days I was just really tired and I can't even remember if I was sick. I honestly can't remember very much at all. I just remember standing there and, sort of going like this [swaying], and it's really amazing because, if you stand with your feet firm, I was just so tired, I'm sure I just nodded off and woke up. I think your body just naturally balances itself or something. I don't know. I was standing up, I could hardly stay awake. Then, I think, I just got out and crawled back to bed. I think I literally did crawl back to bed. I didn't even have the energy to walk. I don't even know why I got up to have a shower. I can't honestly remember. I can just remember being there thinking, ‘Oh my God, what's my life come to?’ [laughs] Standing here like a statue ... it was really scary and at the same time it wasn't because I was just so far out of it. I just didn't know what was going on and I was too tired to care. I really was. It was only later, when you start to get better, that you actually start to get all the mental processes going along, like, ‘Shit, this is pretty awful’, but by that stage, it's not actually as awful.

Suicide was discussed by both ill and recovered participants. Several recovered participants expressed not wishing to recount these suicidal moments in depth in the interviews as this required them to remember times they preferred not to revisit.

A small number of participants, both ill and recovered, expressed that the possibility of “becoming institutionalised” through “receiving” a “mental illness diagnosis” was both “threatening” and “frightening”.

I14: It was frightening. Probably one of the most frightening things I've ever been through. ‘God, I'm going to end up in Cherry Farm⁷³.’ [laugh] I did, I honestly thought, ‘God I'm losing the plot here’. That's when I want to die. ‘I can't cope, this isn't me. I don't want to be this person. I can't deal with being this person’, so I just wanted to crawl under the carpet and just hide. That's not a good feeling.

Being unable to communicate effectively and feeling very weak contributed to the participants’ sense of vulnerability in this respect.

Many of the ill participants described “fear” as an emotional impact of CFS, particularly “fear” of “surrendering” to or “acknowledging” the illness and the impact that the syndrome was having on their lives.

BH: The fear of surrendering to the illness, to the ill feeling. How did that work?

I21: I think it was a fear of dying. It would just be all consuming. I think, partly, I had this picture in my mind of what my [relative] is like and it felt like, if I surrendered, I'd just be like her forever. So that fear, it's part of the mentality I had of ‘I'll just get on with it’ too ... not wanting to acknowledge that you have actually got a broken leg or your leg's just been blown off.

⁷³ Cherry Farm is a colloquial term that refers to a New Zealand rehabilitation centre for mentally ill patients.

These participants commented that the fear of surrendering to the illness was a “drain” on their energy.

Almost all participants, both ill and recovered, describe a sense of “powerlessness”, of being “out of control”, feeling “hopeless” and “despairing” as emotional impacts of CFS.

I29: I just felt powerless, I felt powerless to do anything, totally and utterly powerless. That was how it felt really, like I just didn't have any choice ... A state of dread or fear that things are out of my control. There's nothing I can do. I just have to sit back and take what comes to me. Not a very powerful place, really.

I9: It just gave you this terrible feeling of hopelessness when you found that you had tried all sorts of things and nothing worked. You went to different doctors. It's hard to describe really, you just felt, ‘Where do I go from here?’

I10: Despair is the process we all go through, when we're letting go of illusions and unrealistic expectations and finding out just who we really are, finding the real self, our strengths and our limitations, what I'm capable of, what I'm not capable of.

Other emotional impacts the participants described included feeling “depressed”, “repressed” and “oppressed”. The impact of these feelings was a loss of any sense of “joy” and “trust” in life and a fragmentation of self.

I10: My spirit was so depressed, oppressed, that I just didn't have a sense of who I was ... There was just no psychological energy at all because all I could do was get through the day by making sure that we didn't end up in chaos.

The emotional impacts the recovered participants retrospectively recall and the ill participants describe contrast strongly with the recovered participants' accounts of their recovery (section 8.12). More so than their experience of feeling suicidal, it is the fragmentation of self due to the emotional impacts of CFS that the recovered participants are least willing to recount.

I10: I had a dream this morning before I woke up and it was around a client who I was visiting and she was in terrible despair. And I was looking out at trees in this dream, outside her house and thinking how beautiful the trees were, just absolutely glorious trees, and she was unable to appreciate them. She didn't even see them. And I woke up and I thought, ‘That was me. I saw nothing.’ Nothing, except the task in front of me that had to be done and that was what my life became and it began during that eight months. So the joy of life was totally missing, there was no joy in life, whatsoever, none. [laughing] Who wants to remember that?

Regardless of whether the participants name an impact of CFS as emotional, the impact isotopy is thymic throughout. Whether it is the grief associated with the lack or loss of status, confidence, independence, validity, definition, power, identity or self-esteem or states of fear, judgement, hopelessness, despair, depression, oppression or repression, the impact isotopy consistently connotes dysphoria that is sometimes extreme. Underlying this dysphoria is a state

of disjunction with being-able to-do and to-be. The participants actorialise⁷⁴ the illness through individuation⁷⁵ by engagement⁷⁶ in order to narrate it as something that impacts on them. Within the impact isotopy, the syndrome as actor⁷⁷ is portrayed non-figuratively. This actor is very abstract. The participants say little about how, pragmatically, the illness impacts on them despite the fact that, by its very nature, an impact is something that connotes transformation, whether this transformation is dysphorically or euphorically experienced. The impacts isotopy is related consistently across the Wellington and Christchurch participant subgroups.

8.11 Relating to the Illness and Employing “Coping Strategies”

Many of the ill participants expressed that “positioning” themselves in relation to the illness and retaining a separate sense of self definition were made difficult by the all consuming and unbounded nature of the illness. Nevertheless the participants actively negotiated how their illness was defined in their relationship to it (Figure 13).

Several participants, both recovered and ill, saw CFS as the ultimate form of “dis-ease” with oneself.

I23: It's hard to label it. I think that's been the problem the whole time. What is it? It's the ultimate dis-ease. A human being is at war with themselves, in whatever way, whatever issues they have brought into their lives. So, I'd just classify it as a dis-ease.

Some of the ill participants confront the illness and tell it to “go away”.

I5: Sometimes, I tell it to go away, I don't need it anymore. I've got this great life ahead of me, it'd be even better if it wasn't around. I just don't need it anymore, there's absolutely no reason why. I try to belittle it.

Other ill participants described CFS as quite separate from themselves. They perceive it to be “masking” their “real” self, the person beneath the mask.

⁷⁴ “1. Along with temporalization and spatialization, **actorialization** is one of the components of discoursivization, and, like these two, is based on the implementation of the operations of engagement and disengagement. What characterizes the procedure of actorialization is that it aims at establishing the actors of the discourse by uniting different elements of the semantic and syntactic components” (Greimas and Courtés 1979, p.8).

⁷⁵ “2. In narrative and discursive semiotics, the concept of individuation is part of the problems connected with the actor – be it individual (a character) or collective (a group) – insofar as the actor is defined as made up, at a given moment of the generative trajectory, of structural properties which are both syntactic and semantic in nature” (Greimas and Courtés 1979, p.155).

⁷⁶ “1. **Engagement** is the inverse of disengagement. The latter is the effect of the expulsion from the domain of the enunciation of the category terms which serve as support for the utterance, whereas engagement designates the effect of a return to the enunciation. This effect is produced by the suspension of the opposition between certain terms belonging to the categories of actor and/or of space and/or of time, as well as by a negation of the domain of the utterance. Every engagement thus presupposes a disengagement operation which logically precedes it” (Greimas and Courtés 1979, p.100).

⁷⁷ “Historically the term **actor** has gradually replaced character (and dramatis persona), indicating thereby a greater desire for precision and generalization – a magic carpet or a business firm, for example, are actors – thus extending its use outside the purely literary. 2. Obtained by procedures of engagement and disengagement (which belong to the domain of enunciation), the actor is a lexical unit, nominal in type, which, once incorporated into the discourse, may receive, at the moment of its manifestation, investments of surface narrative syntax and discursive semantics. Its semantic content proper seems to consist essentially in the presence of the seme of individuation, which gives it the appearance of an autonomous figure in the semiotic universe. An actor may be **individual**, (for example, Peter), or **collective** (for example, a crowd), **figurative** (anthropomorphic or zoomorphic), or **non-figurative** (for example, fate)” (Greimas and Courtés 1979, p.7).

I5: I don't actually think I'm sick. I know that sounds sort of silly. Here I am lying in bed. I can't remember some of the questions that you ask, but I don't actually see myself as a sick person. I think, basically, it's all there but it's just not all there at the minute. It will come back and it's just a matter of waiting until it comes back again.

A small number of ill and recovered participants, retrospectively described CFS as an event that would “come to pass”.

I5: I heard a sermon once, a woman, she used the King James version. Are you familiar with the Bible, the archaic language that they use? She read ‘And it came to pass, and it came to pass and this came to pass and that came to pass’ and I thought, well, ‘Why is she reading that?’ What she was trying to get across is things come and they go. I can't remember anything else she said, but that's what I remember and I've often remembered that. Things come so they will go, but sometimes it takes an awfully long time to go.

Ill participants present the illness as having “power” and agency. “It” has “control over” their lives.

I28: The big power of the disease is losing a lot of control over your body and your circumstances. I'd just come into adulthood, gained my independence and all of a sudden it was gone.

Many of the ill participants described bargaining with their CFS; negotiating the position of power they perceived the illness to have.

I11: [laughs] I don't want to be a slave to it and I don't want it to be the number one thing in my life. I don't want to explain who I am and what I am to someone based on the illness. It's there, I acknowledge that, but it's not all that there is. I want to manage my energy and I want to manage the symptoms. I don't want them to run my life or control it more than they have to by the sheer fact of their existence.

These participants try to reclaim “control” by “being in control” of the illness rather than it being in control of them.

Almost half of the ill and recovered participants described CFS as a “teacher”. What this teacher teaches is how to stay in contact with the body in the “present”. For the participants, “being” with themselves in the present requires “learning” to “listen” to their “bodies” and their limitations.

I21: It feels like it's been a great teacher and it still is. Like this last week, when I got really run down again, it just draws me back in again and it draws me back towards whatever is going on.

I5: Well, depending on just how bad it was, I think the next step was dying. Sometimes it seemed an effort just to breathe. I just used to try and make myself as still as possible ... it wasn't anything I could run away from so I just had to be. That's right now. That used to be a saying of mine, for a while, ‘We are human beings, we are not human doings’. In so much of our society, you only get credit for what you do; that's not being. I just tried to be, keep quiet and calm. I didn't really have the energy to do too much thinking. Sometimes I could cope with the radio, sometimes I couldn't. Sometimes I just lay there.

I26: I think this illness has been a wonderful teacher. I mean, it's been a fucking awful teacher, [laugh] but it's actually been probably the only way I'd learn. [laugh] I wish I could have learnt these lessons easier, but one of the things, I think, is learning to listen to my body, learning to be with myself, to value myself for being, not just for doing ... I've learnt to believe I'm valuable for being, not just for doing. There are little things, like, people say to me at different times, that if we were meant to do all the time, we would have been called human doings. [laugh] Little things like that, which help me to remember, a real learning about accepting myself how I am a lot, a real learning about living in the present. I have this little thing that I say to myself, ‘Expect nothing and then everything is a bonus.’

In response to CFS as a teacher, the participants reassess how they have constructed their sense of “self worth”. Rather than base their “self esteem” on culturally approved achievements and those things that they have “done” and continue “to do”, the participants described valuing themselves simply on the basis of being. From this perspective, the participants place value on “human-being” as well as “human-doing”, considering each “human-being” as having their own personal value quite apart from what that human-being may or may not have done or achieved.

The participants describe “fighting”, “accepting” and “surrendering” or “letting go” of the illness. Fighting “it” is the participants’ most common first response.

I14: The first six months, I fought it. I cried all the time for the first three months, which I've never been like. I couldn't accept the change in who I'd become, not only physically, but mentally as well. And so I did the big, ‘This isn't me, I'm going to fight this every step of the way’. I cried every day, I think, for probably about six weeks and that was when I was not diagnosed and they had me on steroids and antidepressants, which I refused, basically because I kept saying, ‘I'm upset because I'm ill, I know I'm ill, I'm not depressed, I know myself.’

I4: It just slowed me right down. I'll have days that weren't so good and days that were a bit better, so I'd try and do something on the better days, like go to the gym, and then I'd just crash the next day. So I wasn't, at that stage, listening to my body, I was still fighting it, which I think most women do when they're sick. They keep going, and I've learnt not to fight it now, but it took me until I got sick in June to stop fighting it and to just go with it, accept it, and just use my limitations and know if I wasn't feeling well that I had to do that. I have to cook tea at night, I have to do the washing so just pace your day to do what you have to do and if you want to do extras, well, they come afterwards.

I7: Definitely. I think anyone and everyone I've spoken to who's got ME will tell you that. That when this thing is coming over them ... fighting against it, there's absolutely no juice down that path for anyone, ever.

Many of the ill participants describe “quickly” recognising that fighting the illness is not fruitful and instead they work towards “accepting” the illness.

I13: Once I'd turned a corner, I accepted it, decided that I wasn't going to fight it anymore. I just decided to get on with my life. Prior to that, if someone had said, you know ‘do x, y, z’, I mean, I would have done it if it would have been the cure. I would have done anything for the cure, but the cure will come along. I'm not that fazed about it now. It will happen and when it does, great! I'll be first in line. [laughs]

This acceptance is not common in the recovered participants’ narratives.

Almost ubiquitous to the recovered participants' retrospective accounts but less common in the ill participants accounts are descriptions of a process of "surrendering" to the illness. Surrender is distinguished from "resignation". Where resignation is considered to be a form of "despair" and "defeat", surrender requires a "deep honesty" towards "what is" and a clear sense of "being present in the moment".

I21: In moments, my more healing moments, I've surrendered to whatever feeling, what is actually present at the time. Whether that's been a thought, that I feel bad, just surrendering to what is, whether it's my mind that is telling me I'm bad, when in fact it's just my mind that's doing something, or whether it is actually that I feel physically sick. I have surrendered to it at times. Surrendering to me is actually just being present with what is. It's not saying 'okay illness, take me over' it's just like 'okay, so what are you, what is this, what am I experiencing at the moment'.

I23: I think the key thing, given that I've used a lot of references to combat and being at war, the most fundamental thing to start, was to surrender. I let go and it was scary. One day, I was just walking along and it suddenly came to me what I needed to do. I saw this huge, big samurai warrior standing before me and that was M.E.. All its armour and the glittering swords and I realised if I tried to fight it, it would just set me up. I would die. If I surrendered to it, it would just completely vanish and let go and dissolve. The energy that I was feeding it was no longer there. It would just fall to pieces and then, once that happened, I knew I was just a naked soul and I had to learn through soul inspiration to rebuild as my soul wanted me to be this lifetime. Because I've always been a fighter and in Western culture we always admire fighters. You've got to fight this. You don't; you give way to it. It's not like surrender as in give up, take to your bed and never get out of it. It's give way, just let it go, let it pass by, don't resist it, don't battle with it, just give way. So essential.

Many of the recovered participants considered the moment in which they identified the ability to surrender to be a "turning point" from which they were able to "recover" from CFS. Many of the recovered and ill participants express recognising at this turning point the "need" to "care" for themselves.

I21: It's horrible, just awful. It was one of those days when I'd really felt like I had to go to work and I'd just pushed myself to go and I felt crap the whole way in there but I just kept pushing myself and saying, 'You'll be alright, you'll be alright.' Then just not actually being able to walk, just being so physically exhausted that I just couldn't walk. All I could do was cry. And it was all about just not being able to make the decision to actually honour how I felt and just think, 'Well, you're not well, just look after yourself.' It was kind of like all the things, I should be at work, I NEED to be at work, someone's expecting me to be doing something today, I need to show myself and all that sort of stuff. The crying was kind of partly about that, too. It was more, 'Just look after me, I'm the one you're supposed to be looking after here, not everyone else in the world.' So that's just partly what the tears are about, but what was really tough was complete exhaustion.

Both the ill and recovered participants described a number of "coping strategies". When participants were "extremely" ill, they described concentrating on achieving nothing but the "absolute essentials" required to "survive".

I10: My way of coping with it was to do only the essentials, the absolute essentials that had to be done. That just meant survival.

At times of “extreme” illness and with no other choice, the participants described functioning on “autopilot”.

I13: It is a coping mechanism, that I know there are certain things I have to do and I just have to do them that day, that moment, and I just switch into autopilot and I just do it.

The participants described being “proactive” at times when they were more able.

I21: The doctor, he'd just sort of said ‘Well, yes, you look as though you've got the thing they call post-viral syndrome and there's nothing you can do about it, just rest up.’ He had recognised that there was something wrong and he wasn't saying there wasn't anything wrong but he wasn't actually giving you anything more constructive than that. The naturopath had obviously treated other people and obviously was talking about people who had got better and that sort of thing. It was a bit more hopeful and it was a bit more like, ‘Well we can actually do something proactive here rather than just resting.’ That fitted in with my whole picture of what was starting to develop about health. You actually have to help the body get better as well as doing other things to help yourself.

Several ill participants described attempting to ensure a balance of physical, emotional and mental stimulation as a way of coping with CFS and redefining their concept of health. Both recovered participants, retrospectively, and ill participants stressed the need to “resolve” any emotional issues to ensure that they remained as balanced as possible and could use the energy that was available to them as effectively and efficiently as possible.

I11: I certainly don't want to be in any worse shape than I am now. All of my energy management, my trying to keep up with what's happening in the research, supplements and diet, trying to make sure that I have physical activity as well as mental activity during the day. Ensuring that emotionally I've got a good handle on what's going on and I'm dealing with frustrations, disappointments, hurts or whatever because, in a way, if they sit around and fester, they use energy. I want to be able to carry on doing at least what I can do now.

A number of participants sought out experiences that were possible despite their limitations. One such opportunity was exploring “spirituality”. Participants commented that “exploring” their spirituality enabled them to feel “less limited”.

I15: Although you are physically limited, I found that, spiritually, I've got a lot stronger and I think that has been a propping up thing. That has helped me a lot, I'm sure. I have more of an awareness of who I am and where I am going. It's been quite important in my life.

To keep a positive approach to “the future” several ill participants described keeping “lists” of the activities they intended to do.

I11: I have a list of things that I want to do. Some of them require, perhaps just a little more energy than I've got now so they are in the foreseeable future. Some require quite a significant amount, which is going to be a little bit further, and some will probably require that I am more like about 95% fit and well.

To cope with the memory and cognitive difficulties, the ill and recovered participants related making lists of everyday activities. Several ill and recovered participants considered it

important to be able to “laugh” about their memory and cognitive difficulties. By “laughing” about these difficulties, the participants experienced them as less eroding of their identity.

I13: For a while, there, I had to write notes everywhere and I mean even numbers that I ring all the time. Sometimes I'd go to pick up the phone and, bang, it's gone, and I have to go and look it up or I'll mix up my numbers. I just live with it. I just deal with it now, laugh about it. If it is something really important that I have to remember, I will write it down and anything to do with my work, I will write down but if I forget something I forget something. If it's not a major thing, it's no major deal to me. I can't afford to get upset about those things. If I get upset about silly little things, it's going to stress me out and stress makes me worse. I went out shopping and I lost the car in the car-park and we all just cracked up laughing. I've been there, done that, so you don't have to explain yourself. You can just laugh about it and, I mean, they say laughter is the best medicine. I mean, it certainly helps to have a good laugh. I mean, if you laugh too much, then you start to ache again. You just laugh and deal with it.

Both recovered and ill participants stressed the need for activities, events and circumstances that allowed them to feel happiness.

I28: The happiness thing was a really big thing, making sure I did things that made me happy. Even if I couldn't get out of bed, I found ways to distract myself. You become an enormous survivor actually, with this illness, you really do. I also realised that, once I stopped fighting the situation and went with it instead, accepted it, and just lived for now and tried to make that now as present as possible, it really was much easier, and that was my biggest coping strategy.

One ill participant used writing about her experience as a useful coping strategy.

I11: Wonderfully cathartic at times, absolutely wonderful. I had thought that I had dealt with a lot of issues with my ex-husband, for instance, and, when I came to write in the book how I remembered that he had treated me ... I got angry and realised the hurt and the disappointment and the frustration that had built up, which I had squished and sat on, in terms of not getting support from someone who I loved and who I thought loved me.

Connecting with local and national support groups and reading books on ME were coping strategies described by many ill participants.

I18: She [support group representative] had some really good advice, useful stuff. I said ‘I can't meet with the group because I'm working’. When the group was meeting, I was working and I was a little bit unsure about joining the group. She told me of the national group and how to get the subscription to [newsletter], which I did. She also said there's a really good book out. I rang up about twenty bookshops and finally got it at one and bought that and that was really good.

A small number of the recovered participants recounted receiving support and advice from support groups. Recovered participants stressed the need to distance themselves from such groups when necessary.

Consistent with the impacts isotopy in narrating their relation to the illness and coping strategies, the participants' position the illness as a non-figurative actor. In some cases, when the illness is described with anthropomorphic qualities, as being a teacher for instance, the participants consciously portray this actor figuratively but they do so as a metaphorical device. In

both cases, the illness is portrayed as having agency⁷⁸, power and control over the participants' lives. It is this unbounded, all-consuming agency that the participants need to negotiate their relation to, cope with, and define themselves with respect to, and in so doing, the participants create a coherence which provides a sense of junction with the object of value: control. The illness as agent is not narrated as possessing intention. It does not intend to teach, control or exercise power over the participants. It remains a phenomenon rather than becoming a person or possessive entity. In relating to the illness, the participants respond to the agency of the illness by evaluating their relationship to being-able-to-do (being a human-doing) and being-able-to-be (being a human-being) and the value they place on these states. These evaluations represent interoceptive processes that reference transformation. The participants' narrative description of coping strategies is more pragmatic. Unlike the impacts isotope, the narratives considered in this section are not predominantly dysphoric; they are more thematically varied. These narratives are presented consistently across the Wellington and Christchurch participant subgroups.

8.12 Recovery

Even given the significance of the gesture of surrender discussed in the previous section, the majority of the recovered participants described their physical recovery from CFS as a “very gradual process” (Figure 13). The majority of the recovered participants did not identify any specific treatment as responsible for their recovery or “catalyst” to the “healing process”. The participants comment that this “gradual progress” towards “wellness” is “difficult” to identify as it is hard to distinguish from the ups and downs of the illness process.

I8: I improved slowly, all the way along, but it was, it was slow ... You didn't really know whether you were getting better, or whether you had eaten the right things, or whether you were just having a bit of a breather, before the next wall hit you. You didn't really get too optimistic, because quite often you'd start to think, ‘Oh boy, I'm feeling better’, and then, wop, down you'd go again. So you got to be pretty cautious, really. I tried not to spoil my good days, by not being too pessimistic, but I guess my family started to notice, more than I did, that I was able to do a little bit more, and that I was feeling a little bit better; was starting to be able to take on little things again.

I9: It was just such a gradual thing. Slowly, it just took such a long, it was a long slow process, until you really felt any better. But it was probably so long and so slow that you didn't realise what was happening.

One participant did describe a “catalyst” to her “healing”.

⁷⁸ According to Martin and Ringham, “semiotics employs the term agent (or operating agent) to designate the narrative role of a **subject of doing**, that is, of a subject engaged in the carrying out of a particular narrative programme. It contrasts with the term **patient** which designates a **subject of state**” (Martin and Ringham 2000, p.23). Greimas and Courtés do not directly define agent or agency but provide the following definition of the subjects of state and doing: “consequently, there correspond to the two types of elementary utterance (the utterance of state and being, and the utterance of doing) two types of subjects: the first type consists of **subjects of state**, characterized by a relationship of junction with objects of value ... the second type consists of **subjects of doing**, defined by the relationship of transformation” (Greimas and Courtés 1979, p.321).

I10: It was this diet that healed me. It was the diet and the resting and the supplementary stuff that I took, which is included in the diet of course. I read the thing through. I remember it was a Saturday, my family were away for some reason that weekend, so I went on the diet that very morning. About this time of the morning it was, on a Saturday, and when they came back on Sunday evening I just announced that I was now on this diet and I was going to heal myself and I knew I would. I just knew it. And I did.

Although this participant claims that the diet made a considerable and noticeable difference within days, the overall physical recovery that followed this breakthrough is similarly gradual, like the recovery described by the other recovered participants.

Adopting this diet enabled the participant to make a “psychological shift” that is described by the majority of the recovered participants.

I10: I think what was really healing was that sense of being in charge. And so I got my power back, like, ‘I’m in charge of this, I know what I’m doing, and I know this is working’, this complete confidence in it, in the information I’d got through my reading, which I had checked out here with a naturopath I went to. ... That was all my goal was, to get through the day and that sense of powerlessness and hopelessness and being out of control. I had no control over my life at all and, so, what the diet did was I shifted totally on that. I was in charge of my life and no one was going to, no one would convince me that this was a stupid thing to be doing or anything else ... That’s how totally determined I was and how totally I owned my life all of a sudden. Probably for the first time in my life, I felt in charge of my life, totally. And, you see, the psychological shift for me in that was absolutely amazing because it’s always what I’d wanted ... Yes. From powerlessness to power, more than ever. It wasn’t just back to how I’d been but way beyond, that sense of autonomy, of total autonomy in my life. And that happened quite quickly. And it was the diet, of course, sticking with the diet, that became the kind of vehicle for that.

For the majority of the recovered participants, this psychological shift involved “feeling” “in charge” or “in control” of life, having power and “feeling empowered” through ownership and knowledge of their “self” and their “life”. Some participants described this psychological shift as a new sense of “autonomy”.

For many of both the ill and recovered participants, recovery required “hope” and “confidence” in their ability to heal. All participants related the “importance” of knowing of others who had recovered. Knowing others who had recovered gave the participants an ability to retain hope in their own recovery.

I26: That sense of mirroring, having someone else who knows what you’re going through and feels quite well now, and quite recovered - that’s very hopeful.

Almost all the recovered participants described a “sheer determination” to “overcome it” that they claimed was necessary alongside “hope” and a sense of “empowerment”.

I9: Just sheer determination to overcome it, I think. Not to succumb to something that would have been easier to just lie down and give up to. I forced myself to go ahead and do things and go out ... I forced myself to go back to work. I thought ‘I can’t just lie here like a vegetable’. It’s awful, it was just unreal, really, the feeling that it gave you.

Many recovered participants described recovery as involving “spontaneity”, “joy” and “celebration” and requiring a “trust” in the “healing process”.

I21: It's a conscious focus. It's a spiritual trust that I am well now. I'm walking the path where my soul is leading me, share joy at lifting things, joy at walking, joy at running up a hill, celebrating it all the time, noticing, doing this sort of thing [referring to interview].

I28: Have you ever heard of the Zen ideal of a moment of clarity and stillness and nothing else, you just are and that's all there is and this certain joy in that? It's like that. And just being, just having hands attached to your body that you can see and feel move. Obviously, it's much easier when they are not agonisingly painful but lying in a pool of sunlight. Or very simple, little things... a hot shower.

Unanimously the recovered participants described “learning” to “listen” to the “self”.

I30: I can focus quite a lot, if there's trees, like in my garden. I can sit out there and I can think about something and have the answer come to me, that sort of thing. Feeling the grass under my feet. Feeling like I was at one with the universe, rather than the concrete jungle. And I can then listen to my body better. I can hear what it's saying, I can sit and logically think about how things have happened, why they've happened, and what it might mean. What I'm supposed to learn from it. What are the lessons, why was I in [place], what did I have to learn? What were the good things I had to learn from the relationship, what were the bad things I had to learn and have I learnt them and if I haven't, what the hell am I doing? Sometimes it's hard to find that inner peace, that trying to find out what you really want, what's important.

Listening provided an opportunity to examine the significance of life experiences. Listening to the self enabled the participants to “hear” what their body was “communicating” to them. Often, what the participants’ bodies were communicating to them was the need to rest. All of the participants claim that “honouring” the “need” to rest was crucial to their ability to “heal”.

I10: The body needs to rest in order to heal ... What sort of resting did I do? I tried to have a snooze every afternoon, and once the children went to school, I would have a sleep after lunch everyday. I did that for years and years and years. On the days that I wasn't working, I would have that extra sleep. I didn't interrupt my night sleeping. I could still sleep all night as well. I learnt to put my feet up even just for five minutes at a time and just lie down, put my feet up. Take long baths and just lie and do nothing, really. Which was new for me. I developed the ability to lie down and do nothing and just look. It wasn't actually totally new for me because I used to do it when I was a child on the farm. I would just lie in the long grass and watch the clouds. Well, that's not doing nothing, that's an amazingly important thing to do. I'd sit up a tree and just watch the birds in their nests or talk to them or hang upside-down swinging from a branch and just do nothing. Which isn't doing nothing at all [laughs]. I came across a quote recently, in a restaurant, ‘If you're doing nothing and enjoying it, you're not doing nothing’.

Although the recovered participants do refer to the need to rest through “sleeping” and “lying down”, their descriptions of resting do not imply that these forms of rest are sufficient. A state of rest for the recovered participants has resonance with the cultivation of a meditative state. Several recovered participants decided to learn a formal meditative discipline as part of

their recovery process. These disciplines included insight meditation, Tai Chi Chuan and Qigong.

I21: The meditation I do is called insight meditation and it's basically learning about yourself, sitting and watching. When I say sitting with it, it is just like basically sitting with the feeling that's in my body, where the sensations are and just allowing it to be there, really. Just watching it and allowing it rather than distracting myself with something else to make it go away. Rather than racing around and switching on the TV or switching on the radio or talking to someone on the phone, just sit with it, just what's there, staying with it.

I23: You need courage. I found that I needed courage and I was lucky that I had enough just to get me through. I had lots of support too [which] helped. I could just focus on myself. I don't have a kid or partners or anything or houses or businesses to run. I could just focus entirely on myself, getting myself well whereas other people don't have that opportunity.

The recovered participants used this meditative rest to create the “personal space” in which to gather the “courage” they required for their healing. Having the courage to heal allowed the recovered participants to take “personal responsibility” for their healing process.

The recovered participants presented their “healing process” through a number of metaphors and analogies including the “unravelling” of a “complicated knot”, navigating a “maze” and travelling along an “inter-wellness spiral”.

I23: Some people have got the patience to undo the knot. That is what the disease is like. You've got to have a physician and yourself on hand and you go one step at a time and go one knot after another, after another. And it's a maze, it's a trick. Everyone's different, they're all bundled up differently. There could be various physicians that could help along that road. Some can offer physical health: naturopaths, homeopaths, acupuncture, all those sorts of alternative medicines. There's where health lies. The medical profession can only use a sledgehammer, I think, poisons. Alternative therapy is where it's at but I found that, ultimately, it's yourself. You can have instruction from whatever therapist, a homeopathic or a naturopath or an osteopath. You've got to undo this knot first and they'll help you, but you have to do the knot, undo it yourself. And what I found is people that get lost in that maze of illness, it is because they expect someone else to get them right. They are always saying, ‘Can you give me this treatment’, whether it's natural or synthetic and that's not what this disease is about. I think this disease is about a voyage of self discovery and if you resist it, you'll stay stuck in the doldrums.

I27: There's a sort of spiral. It was described to me by somebody who didn't suffer from the disease. I'm not quite sure where he got his information from but he said, ‘It's the inter-wellness spiral’ ... It's like this: you're always going up, but at some points on the turn of the spiral, you're at the lower curve on the way up, so you feel like you're going backwards, but you're actually always going up. So like here [demonstrating], you're actually lower than you were, so you feel like you haven't made progress, you've gone backwards but in fact you are ... but you can't really register the up some of the time. You still feel very much like you're way back when. What happened was that the times when you felt that you were up got longer and longer and longer and the times of being dragged back to a lower point on a curve got fewer and fewer.

What all these descriptions convey is the complexity of the recovery process.

Several of the recovered participants claimed that it is their soul that guided their decisions. For these participants, listening is what allowed them to hear the guidance of their soul.

I23: I mean, gee, if you're going to get well, you're going to have to understand how to deal with it, which is just a practical answer. But also, I think part of the maze that M.E. people walk through and get lost in, is that we, instead of, once again getting back to the soul, trusting that everything is perfect right now, that our soul will lead us through the maze, the head says, 'I've got to understand everything, I've got to be in control'. Therefore that conflict is still there and that's why they get stuck. And I think to some extent understanding is helpful and to some extent, it's not.

The participants described the guidance provided by this soul as “felt” rather than thought. This guidance came from within the “self”; it did not replace the participants’ sense of “personal responsibility” for their healing.

Both recovered and ill participants expressed the belief that there were windows of time within which recovery was more or less likely. In the participants’ opinion, missing one window of opportunity would make recovery before the next window of opportunity less likely.

I27: I was told by people that I spoke to, who have association with ME, I was never told this by my doctor, that if you recover in two years ... you actually have a good chance of recovery. ... However, if after two years, you're still very ill, your prognosis moves out to being ill for five to ten years. If after five years you're still ill, you're looking at fifteen and so it progresses outwards.

These participants suggested that the more windows of opportunity a person missed the less likely their recovery. The participants placed the first window of opportunity at two years from becoming ill, the second at five years and the third at ten years. In this way, the distance between these windows of opportunity increased until, past ten years, the participants believed that recovery was very unlikely.

Many of the recovered participants described “testing” themselves to establish whether they had recovered. Testing involved “developing” and “undergoing” often gruelling tests that systematically established the limits of their ability to “cope”. The recovered participants were concerned to observe any improvements or ground they may have regained.

I23: When I started working full time, I made a commitment to myself to believe that I was well, that the illness had passed and to focus on wellness, wellness, wellness, step into the light. I just really was focusing on that, and still, every day, I maintain that wellness. I think part of it is not having faith and trust that you are well and that's what I committed myself to. I also tested myself, I went 'how stupid can you be?' I went and did this really stupid thing and worked in the most toxic environment I could possibly find on the entire earth, a screen printing factory, a toxic factory. It wasn't even legal, you couldn't see from one end of the building to the other. I worked in it to test, I mean there was no plants that would live in that environment, they would die, and I worked in it for three years [laugh] out of sheer stubbornness. Even though I got fatigued and a bit dizzy, I'd notice those symptoms but commit to wellness ... my body has withstood some tests. I'd notice it has normal flu bouts,

when other people have got the flu, I get the flu. It knocks me back a bit hard but that's because I'm stupid enough to work through the first few days sometimes.

I28: I was in a job where I had to carry stock around industrial sites, and for long distances. Carry thirty kilograms of goods on my back into different places all day. It's a phenomenally physical job, in hot conditions, and I did it. I did it.

Almost all of the tests the participants describe have a physical focus and often relate to the symptoms the participant concerned found the most limiting.

The recovered participants most often considered having more energy to be a sign of recovery. A sense of robustness, particularly with regards to digestion and their immunity, were also considered signs of wellness.

I9: I've got more energy, more get up and go, get things done.

I21: I think that robustness. Physically, when things happen to me, when some stress happens to me, whether it's physical stress, whether it's an illness, whether it's a virus or something, whether it's an emotional upset, whether it's a stressful work situation, my physical response will be much less. Things won't go into the physical level. They are dealt with more at a different level so that it doesn't cause strong physical symptoms.

These improvements relate to the symptoms that the participant found most limiting.

Some recovered participants expressed that their recovery did not change their relationship with family and friends. More often, recovered participants expressed that they became more able to relate to others effectively and more able to enjoy others' company.

I23: I'm relating to people better simply because I'm not so sunk into myself and just feeling much more outgoing. With the old brain working, you can enjoy conversations, you can enjoy talking to people about all sorts of interesting things. If you want to go dancing, you can enjoy dancing, got the energy to dance and to do things. Just getting more enjoyment out of life really. Whatever you do is much more possible than it was.

The recovered participants defined being "well" and "normal" as the ability to do. In this respect a cornerstone of the participants' sense of recovery was the ability to work full-time.

I22: I'm functioning well. I still have some residual bits and pieces, but I'm functioning well with generally sufficient health to be carrying on a normal lifestyle with a full time job ... in contrast to being incapacitated with ME. I mean, my brain works well and memory's not too bad. I'm [job] and I put out the magazine so I'm able to use computer skills, all the multitude of skills to run an office and I'm just able to do these things and put in a full day's work and live a normal life.

I27: As they gave me the job they said 'You wouldn't mind doing it full-time would you?' [laughs] I took a deep breath and thought, 'Well, if I'm meant to be here, I'm meant to be here', so I said, 'Look, you've got to understand I've been ill. I don't know if I can do a full-time job but if you're prepared to have me, I'll do my best.' And, miracle of miracles, I coped.

The recovered participants approached re-entering the workforce with considerable uncertainty. Participants needed to establish their confidence and their ability to function in a work

environment. When recovered participants were able to find a suitable working environment, this contributed considerably to their sense of “wellness”.

Although the recovered participants express that being more “robust” and having the energy to “function normally” gave them a sense of wellness and recovery, many commented that they were not confident that this recovery was complete. Most describe dealing with a residual degree of their symptoms.

I8: I've still got food allergies. Apart from that, if I watch what I eat, I'm okay.

I9: I still suffer from fatigue at times. Get very tired, extremely tired still ... it [CFS] has been a lasting thing. About six years ago, my daughter asked me to make her a couple of maternity smocks and it was still the same. I was still suffering from the same problem. I became absent minded and forgetful at times, just couldn't concentrate on anything. Yes, that was a problem.

The unbounded nature of the illness made “trusting” or “knowing” that recovery had occurred problematic as it was difficult for participants to establish a clear point of conclusion. When was a bout of influenza or a day of fatigue just an isolated event and when was it a potential relapse?

I28: I'm still experiencing that lack of confidence in my own ability to sustain any prolonged effort. I've had this job in [workplace] for a few weeks and I'm sick and I've had to take time off. It's really discouraging. I don't know how long it will take me to get the confidence back and just see it as the flu that everybody else has had and not a sign of my unfitness for the sorts of lives that others have.

Participants who had been ill for extended periods of time, sometimes as long as twenty years, often expressed that it was not appropriate for them to use their previous level of activity as a point of comparison from which to judge whether they had regained full functioning. This created a further barrier to establishing a clear sense of physical recovery.

I10: Well, I would say that I've recovered about ninety-five per cent, almost totally. But it's hard to say because sixteen years is a hell of a long time and I don't know how I would have been sixteen years later because we do age. You know, muscle strength lessens and the amount of puff you have when you walk up a hill is less so it's impossible to say whether I've fully recovered or not. But I feel like I've recovered, intellectually, emotionally, spiritually, a hundred percent.

Many of the recovered participants expressed that by virtue of the fact that their bodies had sustained a chronic illness, it had incurred a degree of “wear and tear” specific to the illness experience.

I23: I knew on a spiritual level I'd learned a tremendous amount. I could never turn back to the way I was. I always watch for conflict and I know that I'm skating on thin ice if I stress my body out. My body now feels like a bit of a rental car: it's been around the block a couple of times, trashed for it's age, so I'm going to need replacement parts a little bit more readily than something that's not... high mileage, that's the word!

These participants remained cognisant of this “fact” and questioned whether they may have lost a degree of their former abilities as a consequence.

Recovered participants commented that there were substantial sections of time during the illness that they did not remember clearly and some periods of time they could not recall at all.

I8: I thought I remembered all this so well but it's hard to go back and think back, probably if I had my children here and my husband and my neighbour, they could probably say, “Oh, you were this, this, this, and this”, but I can't recall. I know that my two girlfriends thought I was going to die. I know that my daughters thought I was going to die. My husband thought I was going die. I thought I was going to die [laugh].

Almost all of the recovered participants expressed some reticence at retracing various aspects of the illness; participants “don't want to go back there”.

I10: It's [laughing] much better to focus on the healing than on the illness. I might be able to go back and talk a bit more about the illness. ... It's just something you don't think about. [laughs] So to talk about it, oh God, to talk about it, will be very hard, [pause]. It's a bit like childbirth. You forget the pain of it, you have to, like, to get on with life, [pause]. Easily the worst experience of my life.

Several recovered participants described a considerable fear about the possibility of the illness recurring and simultaneously refused to consider the possibility that this could happen.

I21: In those moments, there's fear that I'm going to get really sick again.

I9: Surely, to God, you couldn't get something like that again. I've probably got my head in the sand.

The last word almost all the recovered participants wished to offer on their experience, however, was the observation that surviving the illness had made them stronger.

I28: Like with this flu, it's actually been a really miserable flu, but I was walking through work and somebody said, ‘Hi, how are you?’ And I said, ‘Just great’ and meant it, even though I was actually really sick. And I think that's because, comparatively, you feel fairly content, despite being in this physical state that makes a lot of people fairly miserable. What doesn't kill us, makes us stronger.

The psychological shift towards feeling joy, hope, spontaneity, courage, confidence, determination, celebration, trust and feeling in control, empowered and in charge the recovered participants present makes the recovery isotopy the most thymic and most euphoric aspect of the participants' discourse on CFS. These feelings are expressed by a self that is feeling, trusting, autonomous, self knowing and self responsible. The ‘soul’ of this self is, similarly, felt. Listening to the self provides the participants with the ability to-do with respect to themselves and the illness. The recovering self sanctions rest and can be tested for its ability to-do. Although the illness continues to be expressed as both a figurative and non-figurative agent, this individuation is less consistent and the recovering self becomes the more prominent actor, one that does have

intention. This presence⁷⁹ of self in the recovery isotopy brings into focus the absence⁸⁰ of such a self throughout the rest of the participants' discourse on CFS.

8.13 Discussion

This chapter is intentionally a 'compressed' account of the overall experience symbolised in the interview transcripts. The chapter is approximately 28 times shorter than the transcripts. While highly compressed, it covers all aspects of the experience mentioned, even those that may have been related only once or twice. Care has been taken to give sufficient context to each quote to retain the original sense.

The searching for a solution and coping strategies narratives and the narration of the stages isotopy stand in contrast to the rest of the participants' discourse on CFS due to their pragmatic content. Similarly, the stages and making sense isotopes and the interacting with biomedicine narrative express a certainty which contrasts with the uncertainty conveyed by the majority of the participants' discourse. Although the energy isotope has an exteroceptive dimension, the other people narrative is most unusual for its apparent exteroceptive emphasis. In contrast, the majority of the isotopes and narratives contained within the participants' CFS discourse are interoceptive and/or proprioceptive.

Drawing parallels between semiotic nomenclature and the aggregates, exteroceptivity would correspond to an aspect of the first aggregate, the physical environment. The second aggregate, feelings and sensations, would correspond to the thymic states of dysphoria, aphoria⁸¹ and euphoria. Proprioception corresponds to the experience of the bodily aspects of the first aggregate and the bodily feeling of the second aggregate. Interoceptivity would correspond to the fifth aggregate, consciousness, which describes one polarity of the psychophysical complex. The pragmatic dimension of discourse refers to the physical polarity of the psychophysical complex. Operational closure suggests that interoceptive and proprioceptive data have more causal effect on the future states of the organism than the exteroceptive. The participants' discourse on CFS is largely reporting on these aspects of experience which tend toward the consciousness end of the psychophysical complex. This is what the enactive approach would predict of a discourse concerned with experience.

⁷⁹ "In a semiotic perspective presence ("being-there") is considered as a determination attributed to an entity which transforms it into an object of knowing of the cognitive subject. Such a meaning, essentially operational, established in the theoretical framework of the transitive relation between the knowing subject and the knowable object, is very extensive: all possible objects of knowing are present in this case; and presence is identified in part with the notion of semiotic existence" (Greimas and Courtés 1979, p.242).

⁸⁰ "**Absence** is one of the terms in the category *presence/absence* which articulates the mode of semiotic existence of the objects of knowing. "In absentia" existence, which characterizes the paradigmatic axis of language, is called virtual existence" (Greimas and Courtés 1979, p.1).

⁸¹ "**Aphoria** is the neutral term of the thymic category articulated into *euphoria/dysphoria*" (Greimas and Courtés 1979, p.15).

Consistently, the participants' narratives on suffering from CFS convey dysphoria at lack: lacking power, control, certainty, veridiction, normality, energy and sanction that is apparently exteroceptive. What these lacks seem to point towards is a dysphoria with respect to the transformation, becoming not-able-to-do. Like much of the participants' discourse, not-being-able-to-do traverses the mind/body dualism. The participants express an interoceptive sense of not-being-able-to-do that applies to both mind and body. A state of not-being-able-to-do that is embodied in this way would preclude the ability to enact the world. This is consistent with the majority of the specific observations of the experience of CFS. Not-being-able-to-do is most evident in the energy isotopy. What appears to be different in the participants' narration of the recovery isotopy is not just the euphoria⁸² expressed but also the presence of a self that is able-to-do. Such a self would also be able-to-be enactive. It would also appear that the self present in the recovery isotopy has some of the characteristics of an ontologically fragile self. This overview of the participants' discourse on CFS suggests that the participants' concept of self and the energy isotopy warrant further analysis.

Since isotopies of action and enaction, expressed as not-being-able-to-do, are inextricably linked with the illness process, and the isotopy of being-able-to-do to the process of recovery, it appears that CFS may be a disorder of action. This hypothesis is explored in considerable detail in chapter 12 where a general theory of embodied action is developed and related to the CFS illness process. Potential evidence found in the neurological literature to support the hypothesis that the CFS illness process represents a disorder of action is discussed. The general theory of embodied action is also productive of suggestions for the treatment of CFS.

This discussion marks the end of Phase One of the research. This chapter represents the initial formal semiotic analysis of the experience of CFS as this experience was presented by the participants. Subject-specific categories of experience relevant to CFS have been presented within this chapter. Although some of these categories may apply to other conditions, this does not invalidate their relevance to CFS. To the contrary, illness experience found to be in common between CFS and other illnesses could support the contention that CFS exists as an illness process, while experience unique to CFS would support the contention that CFS is distinct. Since this is likely to be the first study of its type, both methodologically and in its application of enaction, there is no literature available to evaluate how much of this illness experience is unique to CFS and what facets are generic to chronic illness. To achieve a comparison between CFS and other chronic illnesses, it would first be necessary that this research be repeated and verified,

⁸² "**Euphoria** is the positive term of the thymic category, which serves to valorize sematic micro-universes by transforming them into axiologies. *Euphoria* is opposed to *dysphoria*. The thymic category includes, in addition, as a neutral term, *aphoria*" (Greimas and Courtés 1979, p.110).

and, secondly, that similar research into other disorders be conducted and verified. From that platform it would be possible to make a comparison in the interests of establishing common and distinct specific illness process experiential categories.

9. Action⁸³ and Self Dis-integration

To the extent that individual desires, as well as cultural practices and the performance of social roles, are developed and enacted most fully in behaviour that is defined by personal and social dimensions, the fuller picture would still require that the notion of self be described in vocabulary that is intrinsically related to pragmatically and socially contextualized behaviour. Who I am is most often tied to what I do, or what I can do, or how I express myself in such contexts, even if such actions and expressions cannot capture the full depth of the self. (Gallagher and Marcel 1999, p.297)

9.1 Introduction

This chapter begins Phase Two of the research. In Phase Two, chapters 9, 10 and 11, a second level of semiotic analysis is applied to the interview material concerning concept of self and the energy isotopy, both of which Phase One determined warranted further analysis. Section 7.9.1 presented the details of how the data was prepared for the second level of semiotic analysis. Sections 9.9, 10.6 and 11.8 provide an enactive analysis based on Phase Two. These sections, and chapter 12, present Phase Three of the research.

Theoretical discussion concerning the self spans practically the entire tradition of western philosophy (Gallagher and Shear 1999, p.ix). Arguments concerning the nature of the self intersect with issues such as phenomenality, the nature of mind and its relation to the body and embodiment. Gallagher and Shear comment:

The variety of responses to the problem of self include assertions that there is no self; that the idea is a logical, psychological or grammatical fiction; that the sense of self is properly understood and defined in terms of brain processes; that it is merely a constructed sociological locus, or the center of personal and public narratives, or that it belongs in an ineffable category all of its own. Among these responses there is no consensus about how to approach the problem of self, much less what the appropriate resolution might be. In short, modern philosophers have rendered both our commonsensical and our philosophical notions of self utterly problematic. The current lack of consensus suggests that the problem of self is a complex and multi-dimensional phenomenon like consciousness itself, and that no one discipline on its own will be able to capture it in an adequate way. (1999, pp.x-i)

Important contributions to a model of the self are being gleaned from Asian theories and practices (Deikman 1999; Forman 1999; Hayward 1999; Kasulis, Ames, and Dissanayake 1993; Laycock 1999; Shear 1999). Numerous theorists consider the role of agency and embodiment with respect to the self (Block and Kissell 2001; Coole 2005; Emirbayer and Mische 1998;

⁸³ “1. **Action** can be defined as a syntagmatic organization of acts, without our having to make any *a priori* decision about the nature of this organization, whether it be an ordered or stereotyped sequence, or programmed by a competent subject. 2. In syntagmatic semiotics, action can be considered as the result of the conversion, at a given moment of the generative trajectory, of a narrative program, either simple or complex. In the case of a complex program, the various pragmatic narrative programs which compose it correspond to the acts which constitute the action. That is to say that an action is a filled-out narrative program, with the subject represented by an actor and the doing converted into a process. 3. Narrative semiotics does not study actions as such, but actions “on paper”, *i.e.* descriptions of actions. The analysis of narrated actions enables us to recognize stereotypes of human activities and to construct typological and syntagmatic models which take account of them. The extrapolation of such procedures and such models can form the basis for a **semiotics of action**” (Greimas and Courtés 1979, pp.6-7).

Esacove 1998; Meyers 1998; Segal 1991). Others are considering processes of self transformation (Esacove 1998; Frank 1993; Murray 2002).

Wells (2003) discusses self disunity in schizophrenia, depression and multiple personality disorder. A number of authors consider the contribution of action to models of the self. De Gaynesford (2002) considers what paralysis demonstrates with respect to the interdependence of perception, action and self-awareness. Brown (1997) presents Mackay's concept of supervisory systems for evaluative activity with respect to action. Brown (1997) understands Mackay to claim that conscious agency is the result of "two fundamental processes: (1) an organism-environment feedback loop of information interchange; and (2) a supervisory system which sets priorities, compares information about results of behaviour to original intentions and makes adjustments to one's 'conditional readiness to respond' to the environment" (Brown 1997, p.499). Kircher and Dick (2003) examine the brain systems that are used in monitoring action and offer a model for consciousness and self-awareness that goes towards an understanding of the relationship between action monitoring and the self. The authors suggest that it is a deficiency in self-monitoring systems that underlies paranoid-hallucinatory symptoms or formal thought disorder in schizophrenia.

Patients with formal thought disorder were most severely impaired in detecting a mismatch between self-generated movements and their visual consequences. This result shows that impaired self-monitoring is, in part, underlying formal thought disorder. ... Taken together, the results show that an impaired self-monitoring ability characterizes patients with a variety of core symptoms of schizophrenia. Given the diversity of these symptoms it seems unlikely that a single self-concept or self-system is disturbed. Rather, it might be useful to think of specific sub-systems that underlie these different symptoms. These systems are connected to a complex self-model that is the result of an interaction of multiple systems that embody intentionality and result in the experience to be a self. One functional principle that may underlie some of these systems is that they generate expectations about what the perceived physical and mental consequences of intentions, actions, and thoughts will be. Paranoid-hallucinatory symptoms and formal thought disorder in schizophrenia could then be conceptualised as impairments of generating reliable predictions in different sub-systems of the self-model. (Kircher and Leube 2003, pp.665-6).

The role phenomenological investigation will play in developing understandings of the self is broadly debated (Brook 1999; Sheets-Johnstone 1999; Strawson 1999; Zahavi and Parnas 1999). Phenomenologically-based models of self are being applied in robotics (Tani 1999) and phenomenological examinations of conditions such as schizophrenia (Zahavi and Parnas 1999), dissociative identity disorder (Radden 1999, 2003), disorders of facial embodiment (Cole 1999) and brain damage (Gallagher and Marcel 1999) are contributing to phenomenological models of the self.

Gallagher and Marcel (1999) observe that traditional approaches to the self tend to begin from a position of abstract reflection, one that does not embrace action. They describe this mode

of analysis as hyper-reflection, “a third-order cognitive activity, once removed from reflexive consciousness, and twice removed from phenomenal experience or the behavioural level at which we find contextualized action” (Gallagher and Marcel 1999, pp. 286-7).

When, for example, philosophers employ reflective introspection in order to search for the unity of consciousness or ‘the self’ as an element in consciousness, they choose a framework for the investigation that is not equivalent to the framework within which people normally act. The introspective framework takes consciousness and the self as objects and thereby fails to capture their role in the realm of action, where they are specifically not objects (Gallagher and Marcel 1999, p. 274).

Instead Gallagher and Marcel (1999) extend aspects of the enactive ontologically fragile self by constructing a model of the self from a starting point that is contextualised and inclusive of action. Such a model of self is necessary for the present research to do justice to an investigation of the relationship between the self and action in the experience of CFS.

The authors’ model of self highlights the importance of access to the self, attention and intention. These three concepts are key to the analysis offered here and in the next chapter. With respect to access, Gallagher and Marcel (1999) comment:

Consider an animal that has no experience or awareness of its actions. It has no access to something that we would call self. We are inclined to say that such an animal *has* no self. The question of self or personal identity is an issue only for an animal which has some access to itself within the context of its own behaviour; *access to ‘itself’* actually helps to make possible *the existence of ‘its self’* (Gallagher and Marcel 1999, p. 275).

That is to say that access to self is constitutive of the self.

With respect to intention, attention and contextualised action, Gallagher and Marcel (1999) comment:

The intentional attitude of a person consists of the content of their current purposive intentions which is itself a function of their attentional focus. It is inferred from the performance of perceptual, motor and linguistic activities, from phenomenological report, and also from the task demands and external situation. The total context of an action is made up of the intentional attitude and the external context, which we see as largely but not totally interdependent (Gallagher and Marcel 1999, p. 276).

Gallagher and Marcel (1999) discuss experimental evidence which demonstrates that the performance of actions varies according to their contextualisation. What these findings show with respect to three kinds of intention—abstract or decontextualised intention, pragmatically contextualised intention and socially contextualised intention—and their corresponding actions—abstract or decontextualised action, pragmatically contextualised action and socially contextualised action—is that “changes in the content and organization of the agent’s intentions result in changes in the performance level of action” (Gallagher and Marcel 1999, p. 280). Actions required of a subject that are only abstractly related to the self are poorly performed in

comparison to the same actions given pragmatic significance or contextualised within a social or cultural context of personal significance. Gallagher and Marcel (1999, p.279) suggest that abstract or decontextualised actions are characterised by both a lack of context and a high level of conscious attention directed to the action itself whereas “in pragmatically and socially contextualised tasks behaviour tends to be more integrated, presumably because the agent’s intentions encompass more than the immediate action itself, their attentional focus goes beyond it, and its significance is part of the larger projects and concerns of the person. ... Personal goals and motives, as well as the social and pragmatics of a situation (always defined relative to the subject), can clearly provide the energizing mechanism which transforms intentions into action” (Gallagher and Marcel 1999, p. 281).

Intentional attitude is characterized by both its level of contextualization and by the breadth of its attentional focus. Attention can be directed inwardly toward the self, or outwardly towards the world, and in each case the breadth of attention can differ, being largely independent of its direction or object of focus.

It is worth emphasizing that the increased breadth of attentional focus, which corresponds to contextualization, does not imply that all such content is explicit in the person’s conscious experience. ... Furthermore, while there is a correlation between the external situation and the internal attitude, they are independent. In one and the same situation a person can change their attitude. Indeed this is just what is learnt in certain meditation and therapeutic techniques (Gallagher and Marcel 1999, p. 281).

Tsakiris and Haggard (2005) investigate the neurological evidence for the model of self Gallagher and Marcel (1999) propose by considering the relationship between efference and afference. In section 11.8 the work of Tsakiris and Haggard (2005) is considered in more detail and brought to bear on the analysis of “energy”.

The analysis presented in this chapter and the one that follows asks how, for the participants in this research, perceived dysfunction with respect to action relates to self perception. These two chapters present semiotic analyses of the self narratives that the participants expressed in their discourse on CFS. The semiotic analysis of each self narrative is then assessed through the enactive perspective. Particular attention is paid to the intentions expressed by each self narrative and aspects of self that each self narrative pays attention to and accesses. Equally important are the intentions, attentions and accesses to self that are not expressed by each self narrative. In this chapter, the retrospective narratives of self which I have called the ‘self before illness’ and the ‘self that becomes ill’ and both the contemporaneous and retrospective ‘having an illness self’ narrative are presented in sections 9.2 to 9.8. These narratives are analysed from the enactive perspective in section 9.9. Chapters 9 and 10 are based on the recoded data from all the clusters other than “body”, “energy” and “biomedicine”. These

clusters contained all the nodes that related to the self and all the nodes that contained a significant difference in contribution between the ill and recovered research participants. What the next two chapters suggest is that, with respect to CFS, the main differences between the ill and recovered participants, in as far as this can be identified through a consideration of the phenomenal data, are the differences in their self perception, what parts of the self the participants access, what the self intends and to what it pays attention.

9.2 Narrating the ‘Self Before Illness’: Recalling Action

Presently, it is not possible to predict who will suffer from CFS. Consequently, it is not possible to identify examples of such individuals’ self presentation prior to the onset of the illness. The participants’ narrative expression of their self prior to illness is an interoceptive account constructed in retrospect. The participants are remembering and recreating a self that cannot necessarily be considered identical to how they might have presented this self prior to their experience of illness. It needs to be born in mind that this narrative of ‘self before illness’ is undoubtedly constructed in relation to the illness experience. All of the participants expressed the ‘self before illness’ at some point during the interview process. It was not usually the first self to be presented.

Most commonly, the participants signalled the inchoation⁸⁴ of the ‘self before illness’ narrative through a statement conveying that, prior to their illness, they held plans for their future that included such activities as overseas travel and having a family.

I17: I've always had things I want to do. I've got tons of things I want to do. With the French I wanted to continue with it and travel and I thought in a couple of years I'd use it and I'd go to France and I just physically can't do that. There's that level of frustration, the frustration at not being able to work. It was hugely disappointing and frustrating to have to stop doing [part-time job] after four or five weeks purely because I'd cracked up physically.

Within this narrative these virtual⁸⁵ plans convey a clear intention to do and are contrasted with the participants’ inability due to illness to realise them. The ‘self before illness’ represents the predictable ability to do and the reliable ability to plan to do.

⁸⁴ “Inchoateness is an aspectual seme which shows the beginning of a process: it is part of the aspectual configuration inchoateness/durativity/terminativity, and its appearance in the discourse allows the realization of the entire series to be foreseen or expected” (Greimas and Courtés 1979, p.154).

⁸⁵ “1. In the framework of the modes of semiotic existence, the *virtual/actual* category permits a characterization of the relation between system and process, between language and speech. Contrary to actual existence, which belongs to the syntagmatic axis of language, **virtual existence** characterizes the paradigmatic axis: it is an existence “in absentia.” 2. Narrative semiotics has been led to substitute the ternary articulation *virtualization/actualization/realization* for the couple *virtualization/actualization*. From this point of view, **virtualization** corresponds to the act of positing subjects and objects prior to any junction (or, inversely, of purely and simply suppressing this relation). In the framework solely of the utterances of state, it is the role of the function to operate their actualization by disjunction and their realization by conjunction” (Greimas and Courtés 1979, p.371).

9.2.1 Energy and Action in the 'Self Before Illness'

The most common isotopy the participants draw upon in their accounts of their former selves is the isotopy of energy. This is clearest in their assertion that they had been 'energetic'.

BH: Could you describe what sort of person you were before you got the ME?

I9: Extremely energetic, very, very energetic. After I had the ME, it was an effort to do anything. ... I just found I didn't have the strength to get up and get cracking. I think that would be the biggest problem and that really upset me because I've always been energetic.

I18: I'm very aware of everything that I'm doing, that it's a really big effort and that I'm using up energy. Whereas, as I say, before, I just did it. I didn't have to almost think my way through each step.

Within the 'self before illness' narrative the energy isotopy is conveyed with considerable coherence evidenced above by the immediacy with which the participants' "energy" was previously available to them, 'I just did it', and in the lexical cohesion⁸⁶ created by the juxtaposing of this immediate availability of energy to their contrasting experience of lacking energy in illness and the repetitive use of superlatives such as "very" and "extremely".

Most of the participants described regularly directing this 'energy' into 'stimulating' activities: sports, hobbies and social events in particular.

BH: What was that person before like?

I14: I was just a party animal. [laugh] I was really energetic, ... I was always going out, especially at university, going out three, four nights a week probably, drinking probably four or five times ... out for dinner. I was always round at other people's places. I was always the one organising everyone to get organised to do something. Always go out for day trips, go away for weekends, life and soul of the party, had loads and loads of friends, was really, really confident, could do anything I wanted basically and then whekk, somebody opened the floor out from underneath me.

The repetitive use of the superlative "always" gives this 'self before illness' an atemporality. The underlying immanent structures⁸⁷ that emerge include certainty, consistency, coherence, unitarity and permanence. This is a concept of self in stasis, one that is not undergoing any processes of transformation or change.

⁸⁶ "Lexical cohesion occurs when two (or more) words in a text are semantically related, that is, they are related in terms of their meaning or content. Common devices of lexical cohesion are: pronouns, repetition, collocations and synonyms" (Martin and Ringham 2000, p.81).

⁸⁷ "1. The autonomy of linguistics – justifiable by the specificity of its object, insisted upon by Saussure – has been reaffirmed by Hjelmslev under the form of the **immanence principle**. Since the object of linguistics is form (or natural language in the Saussurian sense), any recourse to extra-linguistic facts must be excluded, because it breaks down the homogeneity of the description. 2. The concept immanence participates, as one of the terms, in the *immanence/manifestation* dichotomy. The manifestation logically presupposes the manifested, that is to say the immanent semiotic form" (Greimas and Courtés 1979, p.151).

Several of the participants did not use the term energy directly in relation to stimulating activities in the narrative expression of their ‘self before illness’ but nonetheless drew on the isotopy of energy in their descriptions of “thriving” on “stress” and living full lives.

I14: Everyone has different stress tolerance levels, and like I said, I thrived on it before, but now the most simple, simple situations I can find quite stressful and I would never have felt [that] before.

I21: I was very, very busy before, very busy work-wise, doing lots of outdoor activities, social-wise, just busy the whole time and I guess I was quite driven. I did a lot of things because I felt I should be doing things and I was always on the go.

Again, this self that formerly thrived on stress is contrasted with its inability in illness to tolerate stress. The self that thrived on stress was one that was “driven”, “always on the go” and “busy the whole time”. These superlative phrases once more relate to action or doing. The ability to sustain prolonged periods of stress represents the ability to act⁸⁸ or do consistently.

9.2.2 Previous Vocation as Action

A small number of the participants had retired before becoming ill. Almost without exception, the remaining participants mentioned their previous vocations in their descriptions of their ‘self before illness’. Prior to reducing their working commitments or leaving the workforce entirely (as a consequence of the illness), the participants described working as software engineers and computer consultants, air traffic controllers, primary and secondary school teachers, professional athletes, farm hands, executive directors, managers, researchers and home makers. The participants described their work as “important” to them and most commented that they had been pursuing the development of their careers. These participants stated that they had valued their ability to “contribute” to society and “earn” a wage.

I7: I never saw myself being on a benefit in my life, before retirement.

I18: Once upon a time, it was nothing to think about going out to dinner ... I'm more conscious of it financially than I would have been before.

⁸⁸ “1. In the philosophical tradition which stretches back to scholasticism, an act is identified with “causing to be” and corresponds to the passage from potentiality to existence. This sort of definition, whose intuitive nature does not pass unnoticed, is extremely general. Not only can all the “events” which make up the web of narrative discourses be interpreted as acts, but discourse itself is an act, an organized sequence of cognitive acts. Consequently, it is essential to establish a model for the representation of the act that can be used in semiotic analysis and that can eventually form the starting point for a semiotics of action. 2. The intuitive definition of acting as “causing to be” shows that it contains two predicates that are in hypotactic relation. Its syntactic representation will thus assume the form of two utterances: an utterance pertaining to doing (=causing) and an utterance pertaining to state (=being). The former will govern the latter, which will be the object of doing. The canonical representation of an act may be formulated by a modal structure either of the type F $[S_1 \rightarrow O_1 (S_2 \cup O_2)]$ or of the type F $[S_1 \rightarrow O_1 (S_2 \cap O_2)]$ and is recognizable at the level of surface narrative grammar. 3. The interpretation of this formula is simple: to act presupposes the existence of a subject and is identified with the modality of “doing”, producing a state (or change of state) that is formulated as the junction of an object with the subject, which may or may not be in syncretism with the subject of doing. Thus, to act partially corresponds to performance and presupposes a modal competence, considered as the potentiality of doing. This explains why an act is defined as the passage from competence to performance, with “passage” being interpreted syntactically as the modality of doing, which is conversion, at the level of anthropomorphic syntax, of the concept of transformation” (Greimas and Courtés 1979, pp.2-3).

This aspect of the participants' 'self before illness' narrative suggests that work was important to them because it provided them with a performative realm⁸⁹ through which they qualified as competent in their relations with others. It also provided the participants with a sense of their own independence and self-reliance.

Whether it is the participants' account of the intention to carry out concrete plans, the immediate availability of an abstract motive quality such as energy, the ability to sustain prolonged periods of stress, or the recounting of an actualising role such as their previous vocation, the isotopy that underpins the 'self before illness' narrative is that of doing or acting. In this narrative, the participants derive their sense of self agency from their ability to perform or act effectively in the world: to be a subject of doing. This narrative is an interoceptive account of the experience of exteroceptive pragmatic doing. There is little thymic content to this narrative; rather it is the pragmatic dimension that predominates. This pragmatic dimension is monotone in quality and repetitive.

9.2.3 Self Naïveté

Although there is minimal thymic dimension to the 'self before illness' narrative, and the participants positively evaluate all of the aspects mentioned above, there is one exception. When the participants, rather than simply recounting this 'self before illness', instead reflected upon it, those who had been ill for more than six months stated that, prior to illness, they considered they had been, in some sense, "naïve" in their ability to know themselves. These participants noted that they had given little thought to their identity or sense of self. In enactive terms, the participants observe of the 'self before illness' that it does not redirect attention towards itself.

I25: I was a shallow person before ... I can't quite put a finger on it but it's how you relate to people.

I10: Before I had known about my intellectual powers but I hadn't any notion of the depth of my integrity.

I5: I used to hate having to be by myself. I couldn't believe it when I had to stay in bed and spend all my days and all my nights alone. I just have to laugh and think, well, 'Why was I scared to be alone?' I mean it was a form of anxiety. I realised I'm made of sterner stuff than I thought I was.

"Shallow" signals an absence of a dimension of self, one that within the 'self before illness' narrative the participants are not "quite" able to "put a finger on". In contrast, "integrity" refers to the presence of this illusive dimension of self. "Depth" signals that this presence is a question

⁸⁹ "5. Performance, considered as the narrative program of the competent subject, one that acts (by itself), can serve as a starting point for a semiotic theory of action: it is known that every narrative program is capable of expansion under the form of instrumental narrative programs which presuppose each other in the framework of a base program. Interpreted, on the other hand, as a modal structure of doing, the performance – called **decision** when it is located in the cognitive dimension, and **execution** in the pragmatic dimension – allows us to envisage further theoretical developments" (Greimas and Courtés 1979, p.228).

of degree. The dimension of self that “integrity” refers to here is not completely absent but one that nonetheless comes to have more presence. Although this absent dimension of self is not positively identified anywhere within this narrative, through the use of the lexeme⁹⁰ “had”, it is contrasted to the intellect, “intellectual powers”. The question becomes: what kind of integrity is this?

9.2.4 Establishing Veracity

In the ‘self before illness’ narrative, most participants stressed that they had not known about CFS before they became ill and those who were previously aware of the disorder described themselves as having given the illness little credence.

I2: I know myself that before I had ME, and I'd only vaguely heard of it, I thought, ‘yeah, well what a crock is that [laughs]. That doesn't sound like an illness to me.’ I probably was one of those people who had a view of people with ME as being sort've, just something being wrong with them.

The illness becomes something that is at least disregarded by and at most completely unfamiliar to the ‘self before illness’. This distancing of the self from the illness is enlisted elsewhere in the participants’ overall discourse to establish the veracity of the self, something that becomes increasingly more difficult to maintain.

The ‘self before illness’ narrative constructs a temporal space that occurs before and is demarcated from the onset or duration of the illness. It is related with remarkable consistency across participants who locate themselves at very different points through the illness experience, including recovery, and acts as a point of anchorage to which the participants often refer. There were no significant differences between the Wellington and Canterbury participants with respect to the ‘self before illness’ narrative.

9.3 Illness as an Unfamiliar Experience: The ‘Self that Becomes Ill’

In contrast to the familiar, certain, consistent, coherent, and permanent ‘self before illness’ the participants’ retrospective narrative of the ‘self that becomes ill’ presents a self that is unpredictable, indefinable and dysphoric. The predominant isotopy that emerges in this narrative is unfamiliarity or foreignness. This is clearly evident in the participants’ talk about ‘symptoms’ of the illness.

I5: People talk about getting the flu but it was nothing like I'd ever had before.

⁹⁰ For the purposes of this analysis, a lexeme may be defined as “the totality of possible or virtual meanings attached to a particular word” (Martin and Ringham 2000, p.80). For a broader definition the reader may refer to Greimas and Courtés’s (1979, pp.172-5) discussion of the lexeme and lexicology.

I9: It was rather devastating, because I've never been unwell like that in my life before. ... I've had flu bugs before, but this one, I don't know what it was. There was just something different about it. It just knocked me out.

I10: Never had any allergies before ... the difference is that I hadn't had those allergies before at all, never had any.

I11: They weren't stress headaches because my scalp was loose and all that sort of stuff. Unlike any other headache I'd ever really had before. Particularly distressing to me, because it was sufficiently sharp to remove a lot of my acuity.

I12: I was a light sleeper before but I still slept probably eight or ten hours. I was as healthy as a horse, I never had anything wrong with me before I got crook.

I14: I was having anxiety attacks quite badly, panic attacks at that time which I'd never ever experienced before ... weird sensations, headaches that I'd never experienced before, weird ringing in my ears, just really weird cognitive things.

BH: Were there any other allergies?

I15: No, not before I actually had ME. I think I ate really well, slept really well, worked really well.

I19: I noticed how hard it was to study and I'd never had that sort of problem before.

What is striking in these descriptions is the strength of the assertion by the participants that these apparently common 'symptoms' are completely new and unfamiliar. This raises the question of why these apparently common symptoms are experienced in this way. They are "weird" and "unlike" anything the participants had previously experienced. This isotopy of unfamiliarity or foreignness is emphasised by the use of superlatives such as "unlike any other", "never" and "nothing". Foreignness, in combination with phrases such as "just knocked me out", "devastating" and "distressing to me", functions to communicate the abrupt and extreme degree of incursion the experience of becoming ill brings. Within the 'self that becomes ill' narrative the familiarity of the 'self before illness', present by its absence, is emphasised in the examples above through the use of "never" and the repetition of "really". This preserves a consistency between these two narratives.

The 'self that becomes ill' is not well developed in comparison to the other self narratives the participants expressed and was never the first self narrative presented. It is most common in the participants' descriptions of the onset of the illness. Although the 'self that becomes ill' expresses dysphoria, the thymic dimension of this narrative is not well developed. The 'self that becomes ill' demarcates the beginning of the illness experience and is often located at a specific time or in relation to a specific historic life event. The 'self that becomes ill' is presented consistently across all participant subgroups. It represents a process of self transformation that is negatively evaluated.

9.4 Negotiating Stereotypes and an Ambiguous Self

9.4.1 Negotiating Stereotypes

Both the narrative accounts of the ‘self before illness’ and the ‘self that becomes ill’ reflect the participants’ illness experience and are consistent within the participants’ overall discourse. A similarly defined self during illness, an ‘illness self’ narrative, was almost completely absent from the participants’ discourse on CFS. The only examples of a self that is directly described as ill come from a small number of the ill participants’ very tentative contemporaneous accounts of negotiating the stereotyped CFS self that they were confronted with in their interactions with others or found in the literature about the illness. Such accounts of self are exceptional within even these participants’ overall discourse on CFS.

BH: Can you describe to me, that 'fussy ME'?

I15: The perfectionist bit? Well, I don't know if everybody is. I know [name] is and I am. Well, people tell me I try to be, but you can't be a perfectionist at everything. I do have order. I like things to be right.

BH: How do you think that's connected with the ME?

I15: It's not, it's your personality. But I think that's the trend. I don't know; you might find it in your studies. It could be just a personality thing because I don't think it's anything new for me. It's not just ME. No, it hasn't just happened.

I20: The other thing I didn't mention was, well I did, I think, allude to it yesterday, was the natures of people with ME. We're not aggressive people on the whole, and that is interesting, and I don't know whether that predisposes us to some illness like this or not, but I wanted to explain that a little further to you. When we were in [place] the [ME Support] group was combined with the MS group ... and very often when it came to Christmas parties and things like that the two groups would combine. I saw MS people at close proximity, and they were aggressive people and the ME people stood out as being quite different from them. They were not aggressive people, they were much more placid people.

The majority of these accounts of self proposed stereotypical personality traits, such as perfectionism, hypochondria or feminine passivity, that might predispose the participant to the illness. This predisposition was seen as a contributing factor but not as an aspect of the illness *per se*. In the first example, comments such as “you can’t be a perfectionist at everything”, “I don’t know”, “I don’t think it’s anything new”, “it’s not just ME” and “it hasn’t just happened” act to heavily qualify these statements and underline the participants’ doubt about their veracity. Whereas in the second example above, narrating a situation of objective observation “at close proximity” is enlisted to support the hypothesis that the “placid” nature of “ME people” “predisposes” them to the illness. Those accounts, which positively identify the self as ill, are exceptional, to the extent that they stand in contradiction to the principal self narrative related during the participants’ period of illness and this brings the absence of an illness identity to attention.

9.4.2 Self Ambiguity in Illness

More commonly, both the recovered participants retrospectively recalled and ill participants contemporaneously proposed a distinction between an ill self and a self that has an illness. The participants claimed that, because their illness was not recognised by others and they therefore did not receive facilitation in acknowledgment of the limitations the illness created, they were not entitled or could not “afford” to consider themselves ill selves. They were in-valid invalids.

BH: How do you make that distinction, between having an illness but not really thinking of yourself as an ill person?

I5: Because ill people, what do ill people do? Ill people have lots of people fussing round them, ill people go to the doctor a lot. ... An ill person is someone who is in bed all the time, has to be looked after, can't look after themselves, is very low, physically. I don't know whether that means they are going to die, ill people die. I also wonder if by saying I'm ill it means that I need someone to look after me. I think that's what I said before, wasn't it? I think ill people need someone to look after them and I've never had, other than these last couple of years, anyone actually to look after me, so I kind of can't actually afford the image of being ill because there's no one to look after me and the perception is that ill people get looked after. And that's a bit stupid, really, isn't it?

BH: If that's the ill person, what is it to just have an illness?

I5: Having an illness is just getting on with the life you've got with the illness, taking it with you, like carrying a burden with you. But trying to live your life, with it.

Passages such as this demonstrate how the participants attempted to negotiate the semantic category ‘health versus illness’ and how they attempted to situate their sense of self in relation to this opposition. Ill people, representing illness, “can’t look after themselves”, are “very low, physically”, “get looked after”, “go to the doctor”, are “in bed all the time” and ill people “die”. Healthy people, representing health, by implication⁹¹ are physically strong and capable of looking after themselves. They do not need to be “looked after” and do not need to “go to the doctor a lot”. They are clearly “alive” and do not need to spend “time in bed”.

For the participants, the illness experience means that they are “low, physically”, need to “go to the doctor a lot”, “can’t look after themselves” and are “in bed all the time”. In accordance with their definition of illness, they qualify as ill. They do not, however, “get looked after”. Their illness is not sanctioned in this way and it is not clear whether they are dying or not. In these respects, they are placed in a relation of disjunction with qualifying as ill. Neither do they qualify as healthy as they are not “physically” strong, they do need to “go to the doctor a lot” and they are “carrying a burden”, living life “with the illness”. The participants are required to look after themselves even when they are not able to do so. They simultaneously experience illness whilst being required to act as if they are healthy.

⁹¹ “2. Considered as an act of implying, implication consists, for us, in the assertive calling up of the presupposing term, having as its effect the appearance of the presupposed term. The presuppositional relation is thus envisaged as logically prior to implication: the “if” would not find its “then”, if the latter did not already exist as the presupposed” (Greimas and Courtés 1979, p.152).

Representing this on a semiotic square⁹² where health (S1) is opposed to illness (S2), health would by implication imply non-illness (–S2) and illness, non-health (–S1). For the participants, failing to qualify for both the category of health (S1) and illness (S2) means that both the underlying structure of negation (–S2 contradicts S2 and –S1 contradicts S1) and implication (–S2 implies S1 and –S1 implies S2) implode. They cannot communicate their experience through the category of illness, they are not entitled or cannot afford to consider themselves to be an ill person, but neither are they healthy. Analysis of the participants' narrative suggests that the participants solve this quandary by creating an ambiguous state of self, one that lives "with", or carries this contrariety as "a burden". Having an illness but not being an ill person describes this state of ambiguity. The participants' narrative account of the self that has an illness, the 'having an illness self', is discussed in section 9.5 to 9.8 below.

9.5 A Contemporaneous Narrative of the 'Having an Illness Self': Action and Grief

9.5.1 Personal Experiences of Loss

Most often the 'having an illness self' was the first self narrative that the ill participants related. It is the most substantially developed and commonly related self narrative in the ill interviewees' discourse on CFS. The predominant isotopy in the ill participants' contemporaneous expression of the 'having the illness self' was grief. Grief was related directly and through accounts of numerous experiences of loss. The grief is itself experienced as one of these losses. As such, this experience of dysphoria speaks of the participants' perceived loss of access to states of euphoria, in particular the euphoria the participants derived from their ability to do.

I25: It's a grieving process. It is another one of the many losses associated with this illness. You go through the grieving process, sense of loss because you know that you are unable to do that goal.

The participants described their sense of loss or grief as a "day to day thing".

I15: It's a growing thing, too, and it also can be a day to day thing, the grief. Like Christmas day, I was in bed and I had to acknowledge that wasn't very easy. If you're invited out, my friends know now that I'm mobile for the morning and they don't ask me out if it's afternoon or night, and so that's really good. Mostly, I'm pretty reliable. I can go but quite often I have to let myself down or feel I can't do it and that's a day to day grief that I have to acknowledge and get through.

⁹² "1. By **semiotic square** is meant the visual representation of the logical articulation of any semantic category. The elementary structure of signification, when defined – in a first step – as a relation between at least two terms, rests only on a distinction of opposition which characterizes the paradigmatic axis of language. It is, consequently, adequate for the establishment of a paradigm composed of *n* terms, but it does not thereby allow for the distinction, within this paradigm, of semantic categories founded on the isotopy (the "family relations") of distinctive features which can be recognized therein. A typology of relations is necessary, which will make it possible to distinguish intrinsic features, those which constitute the category, from those which are foreign to it" (Greimas and Courtés 1979, p.308). For a more detailed description of the semiotic square see Greimas and Courtés (1979, pp.308-11).

With phrases such as “grieving process”, “day to day thing” and “growing thing”, the participants conveyed that the grief was not necessarily sudden or acute but rather a gradual process whereby their sense of grief developed increasingly over the weeks, months and years of the illness experience. Although not acute or sudden, the participants nonetheless describe this “day to day grief” as “traumatic” and as an “emptying out”. The isotopy of grief forms one of the few strands of continuity within the participants’ discourse on the experience of the illness overall. This escalating grief represents a dysphorically expressed and negatively evaluated transformative process and, as the central isotopy to the ‘having an illness self’, it highlights the predominance of the thymic dimension. This thymic focus appears to be polarised with the principally pragmatic ‘self before illness’. Although dysphoric in comparison to the ‘self before illness’, this thymic dimension is similarly monotone and repetitive. Similarly, despite the continual accumulation of grief the ‘having an illness self’ demonstrates, and the transformational process this accumulation appears to imply, this narrative remains one of stasis in terms of the self that is presented. It is as if the ‘having an illness self’ becomes itself increasingly without beginning or end. This gives the ‘having an illness self’ an atemporal quality.

Specific experiences that contributed to the participants’ sense of loss or grief involved a loss of mobility and the inability to travel, a loss of friends and the inability to participate in social activities, loss with regards to the participants’ ability to work, earn and follow a career path and a consequent loss of status, a loss of identity, actualising⁹³ identities such as vocation or the ability to participate in particular recreational activities and what the participants described as a resultant overall loss of quality of life.

I25: So many losses. More loss of a job, loss of friends, loss of not being able to come and go as I'd like to. Like I had hopes of travelling extensively when I had a career, you know. Loss of self-esteem, the psychological aspect of it, too. Lots of losses, loss of being able to earn money.

⁹³ “1. From the point of view of the modes of semiotic existence, and within the linguistic framework, **actualization** corresponds to the passage from system to process. Thus, language is a virtual system which is actualized in speech and in discourse. In the same way, it can be said that a lexeme, which is characterized as a mere virtuality, is actualized thanks to the context in which it occurs in the form of a sememe. Used within the framework of the *virtual/actual* category, actualization is an operation by which a unit of language is rendered present in a given linguistic context; the actual existence (“in praesentia”) thus obtained is inherent in the syntagmatic axis of language. 2. Narrative semiotics has found it necessary to substitute for the traditional *virtual/actual* pair, the ternary articulation *virtual/actual/realized*, so that a better account can be given of narrative organizations. Thus, subjects and objects prior to their junction are in a virtual position; their actualization and their realization take place in accordance with two types of characteristic relations of the function; disjunction actualizes subjects and objects, conjunction realizes them. 3. From this point of view, actualization as an operation may correspond – insofar as it is brought about from a prior realization – to a transformation which effects the disjunction between subject and object. On the figurative level, it is, then, equivalent to privation. Depending on whether at the actorial level the subject of doing is different or not from the subject, in a situation of lack there will be either a transitive actualization (figurativized by dispossession) or a reflexive actualization (renunciation). The term **actualized value** refers to any value invested in the object at the moment, or in the syntactic position, when the object is in a disjunctive relation with the subject” (Greimas and Courtés 1979, p.9).

I26: Like my identity as a [previous vocation] and all those sorts of things, the [previous hobby], like I'd built this room, that sort of identity. I've still carried on doing part of it but it's only a minimal amount of what it was, so that's part of my identity. Loss of potential earnings: if I was a healthy person I'd have a job and I'd be earning a lot more money. Loss of status. I mean it's actually quite a big one, I think, because people ask me what I do and I find it quite hard to answer.

Although these losses appear diverse, they are also specific. Without exception, they signal the loss of the ability to perform, to be a subject of doing. The participants are articulating that “having” an illness such as CFS undermines their ability to act in accord with their intentions and expectations. With its focus on doing, the thymic predominance of the ‘having an illness self’ narrative which emerges around the isotopy of grief is closely linked to the pragmatism of the ‘self before illness’. The losses experienced by the ill participants ‘having an illness self’ substantially mirror the characteristics of self that all participants related as having in their description of the ‘self before illness’. These parallels are potentially informative. They may reflect the nature of the disorder. Such parallels certainly draw attention to the extent to which the retrospective construction of the ‘self before illness’ reflects the experience of the illness. This suggests the degree to which the ‘self before illness’ is constructed within the process of making sense of the illness experience as a whole.

9.5.2 Others and Loss

Apart from the more obviously personal losses discussed above, the participants also described experiencing their family and other close individuals’ inability to comprehend their illness and, specifically, their loss of ability to do as acutely isolating losses. Others’ lack of “understanding” or “comprehension” culminated for the participants in a significant loss of world.

I26: Many, many losses and not the loss of not having. My personal experience has been my family haven't been able to understand, they weren't able to deal with it. So that was a tremendous sense of loss ... my mother went into denial, I don't think she could cope with it. She couldn't cope with the fact that maybe I'd been active and I'm not the same as I was before, and she couldn't come to terms with that. And just basically swept it under the carpet really to try and not have to deal with it, it's too difficult ... my brother and sister don't have any concept that I'm ill at all. I don't think they believe that I'm ill.

BH: What's that like?

I26: It's horrible. It's a loss to me because they don't have any understanding. It's a tremendous sense, it's a psychological loss because you feel you're isolated from your own family, because they don't comprehend. So that isolates you even more.

Having CFS implies that the participants are “not the same” “active” person that they had “been” “before”. Others cannot “come to terms” with this change, it is denied: “I don't think they believe that I'm ill”, “swept” “under the carpet” and made invisible: “my brother and sister don't have any concept that I'm ill at all”. Further to denial, passages such as this also convey the participants’ sense that there is a resistance on behalf of others to understand or comprehend this

transition, “to try and not have to deal with it”. The participants are aware others find it “too difficult” to face.

9.6 Narrating the ‘Having an Illness Self’ In Retrospect: Facing the Unknown

In comparison to the ill participants’ focus on grief and loss, the recovered participants’ retrospective account of the ‘having an illness self’ described how difficult participants found being “present” during illness. The participants described existing in an “abyss”, or “void”, “numb”, like an “automaton”, neither “dead nor fully alive”. Similar to the ambiguity experienced in relation to the semantic category health versus illness (see section 9.4.2), the recovered participants here struggle with the semantic category ‘life versus death’. The participants are both alive (S1) and experiencing something akin to death (S2). For the recovered participants, life does not imply an absence of death. Instead, the participants describe themselves as existing in a “strange state”, a “living-dead”. This living-dead, numb automaton state is like a motionless “robot”. It is both emotionally and physically numb and immobile and represents emotional and physical absence. This absent robotic state is the closest concept to an ill self that the recovered participants describe and represents a somatic and affective absence of self.

I10: I just wasn't present, you understand? Like it's just so enormously difficult to be emotionally present with everything that was going on and so my focus had to be on the children. I remember more about them than I do about my own life experiences of those years. So the loss is enormous, it's just enormous, for anyone who suffers from chronic fatigue syndrome.

I28: You do, it's just like existing in a void as I've said, there's that whole automaton, sort've, facet of your existence. There is that dream state, that fogginess, the wooziness: it's like you actually are no longer really existing. You grieve for having lived when you're not really dead. It's quite a strange state to be in.

Loss is still present in the recovered participants’ narrative and the use of the superlative “enormous” signals its volume, depth and significance. Nonetheless, more fundamental to the recovered participants’ narrative was their observation that, when they looked back on this not entirely present ‘I’, it was an ‘I’ that felt “unbounded”, “undefined” and “undefinable”. It was an ‘I’ that was at times “terrified” of the illness and its potential to impact their lives. The participants expressed “fear” with respect to the possibility of “losing control” to the illness and described how they felt the illness left them without “choice” and “out of control”.

I28: You just don't have a choice. The big power of the disease is losing a lot of control over your body and your circumstances. Suddenly for me, I'd just come into adult[hood], gained my independence and, all of a sudden, it was gone. Having to sleep, there's no thought or choice about it. You couldn't have done anything else. And how that can be the product of a mental state, I don't know. Often, you struggled against it, bitterly, you wanted to be alive,

you wanted to have your time, you wanted to be with people. You would fight it to the last second and it would still just drag you down. You wouldn't be able to do anything about it. You'd find your eyes closing and your head going back down on the pillow. You're not going anywhere yet, sunshine.

The recovered participants expressed that fundamental to this loss of control was the loss of the ability to “do”, to “act”, to be “able”, “productive” and to “keep on going” when required.

I28: You don't know when it's going to end, you don't know whether you'll ever be good for anything again, whether you'll ever be a productive person.

With its descriptions of terror, fear, loss of control and choice, grief and absence of definition, motion and emotion, this retrospective narration of the ‘having an illness self’ speaks on an abstract level of the recovered participants’ experience during illness of facing the unknown. Unlike the ill participants’ contemporaneous account of the ‘having an illness self’, it is not thematically monotone. The recovered participants displace the isotopy of grief from its central prominence and instead place centrally the isotopy of the unknown. Unlike the ill participants who spoke at length about the ‘having an illness self’, the recovered participants, even when specifically requested, were reticent to discuss these issues, preferring to distance themselves from the ‘having an illness self’ experience by locating it firmly in the past. The recovered participants expressed feeling “vulnerable” and “distressed” in discussing this aspect of the illness experience, as if recalling this sense of facing the unknown was tantamount to reliving the illness.

9.7 Having an Illness as Self Absence: Trust, Confidence and Esteem

Although sections 9.5 and 9.6 above relate a number of differences between the ill and recovered participants’ ‘having an illness self’ narrative, there are also important points of convergence. One of the most significant losses communicated by both the ill and recovered participants was a loss of trust in themselves.

I26: Loss of trust in myself, sort've not being able to trust myself from day to day to be able to, like not being able to say, ‘oh tomorrow I'll do this’ or, if someone says, ‘oh let's go and do this on Sunday’, and not being able to say, ‘yeah I'd love to’ and know that I'd be able, up to it. That unpredictability, unreliability, loss of energy, loss of strength, loss of a social life.

I23: I'd be scared that I'd do something dumb because it affects your brain. It affected me terribly. Like I'd be, ‘God I hope I'm not going to be too stupid today’. Like, ‘could I think clearly, could I work properly, hang out there for a whole forty hours’.

This “loss of trust in myself” was almost always expressed in connection with the loss of the predictable and reliable ability to “function”, perform or “act”.

Emphasised above by the repetitive use of the lexeme “able” and consistent references to difficulty with activities, losing trust in the self in this way often led to a loss of “self-esteem” or “self confidence”.

I25: I mentioned loss of self-esteem because being the high achiever that I was, I always took pride in doing well at things and, when you can't, are unable to do things for yourself, you have to ask for help from others, it's very hard because you've always been an independent person.

I26: In a world where most people say to you, when they first meet you, ‘how are you, what do you do?’ And all I could think of was to say “nothing”. Losing the ability to make social chat, losing the confidence to do that and just really losing my confidence in myself as a worthwhile human being ... that's a great loser of confidence.

I30: Slowly your confidence and self-esteem are just totally eroded ... it just takes away everything that made you feel like who you were and feeling good about yourself, it just stripped you of everything. Now it's really, really hard to try and build up your self-esteem again and your confidence. You go out there and you think, ‘okay, I can do this’. There's always a ‘what if’, like I know in my mind I can do things but what if after that something happens with my health. You know, what do I do?

These passages show directly how the “what if”, the unreliability and unpredictability surrounding their ability to do “took away everything” that made the participants “feel like who you are”. For the participants the inability to place “trust” in the self as a present subject of doing undermined any “confidence” or “esteem” in this self as a whole.

This loss of “confidence” in the pragmatic exteroceptive doing self is so considerable that, even after the participants described themselves as completely recovered, they continued to refer to a persistent sense that they could not trust in their ability to-do consistently.

I28: I'm still experiencing that lack of confidence in my own ability to sustain any prolonged effort. I've had this job in [name of business] for a few weeks and I'm sick and I've had to take time off, it's really discouraging. I don't know how long it will take me to get the confidence back and just see it as the flu that everybody else has had and not a sign of my unfitness for the sorts of lives that others have.

One of the recovered participants problematised this lack of confidence in relation to recovery.

I27: If one had to fight any of the many battles that are associated with Chronic Fatigue Syndrome, it would be certainly helpful if they had some self-esteem with which to do it.

It is interesting that this comment does not contain a first person ‘I’. By using the third person, the lexeme “one” and the phrase “if they had”, the participant creates a distance between the issue they are relating and themselves. This is a similar device to locating the illness firmly in the past (see section 9.6) and performs the same function of creating distance between the participant and the experience of the illness.

9.8 Sanction and Self Dis-integration in the ‘Having an Illness Self’ Narrative

In both the contemporaneous and retrospective accounts of the ‘having an illness self’, having CFS not only undermines the participants’ ability to act in accord with their own expectations but also in accord with the expectations of others. These two are importantly related, since self and other are intersubjectively constructed.

In their descriptions of the ‘having an illness self’, the participants relate their desire to be a receiver and become a subject of doing. The participants clearly communicate the awareness of and desire to accept from the mandatory sender⁹⁴ the mandate to act, where the sender is another party or simply their own internal voice. As such, the participants are willing to enter into transaction with the sender and therefore, where the sender is another party, into the intersubjectivity this contract to act constructs. Accepting a mandate to act creates the possibility of becoming a subject of doing. The experience, however, undermines the participants’ ability to carry through the action required to fulfil this contract⁹⁵. The participants fall short of completing the transaction required and, therefore, do not receive from the sender-adjudicator⁹⁶ the sanction that their mandate has been fulfilled. The participants do not receive sanction for their failed

⁹⁴ “1. The terms **sender** and **receiver** (usually written with a small first letter)-taken over from R. Jakobson’s schema of linguistic communication-designate, in their most general sense, the two actants of the communication (also called in information theory source and receptor, but in a mechanical and non-dynamic perspective). When they are viewed as logically presupposed implicit actants of every utterance, they are called enunciator and enunciate. When, by contrast, they are explicitly mentioned and are thereby recognizable in the utterance-discourse (for instance, “I”/“you”) they are called narrator and narratee. Finally, when the discourse reproduces the structure of communication by simulating it (*cf.* dialog*), they are called interlocutor and interlocutee. In these last three cases it is clear that we are dealing with an act of delegation originating from the sender and the receiver 2. Considered as narrative actants, Sender and Receiver, (in this case usually written with a capital letter) ar actantial domains characterized by a relations of unilateral presupposition (between Sender as presupposed term and Receiver as presupposed term). Consequently the communication between them is asymmetric. Paradigmatically, the Sender is in a hyperonymic relation with the Receiver, while the latter is in a hyponymic position. This asymmetry is amplified in the syntagmatization of these two actants, when they appear as two subjects concerned with a single object. This is what happens, for instance, in the case of participative communication. Sender and Receiver are stable and permanent narrative actants, whatever might be the roles of communication actants that they can assume. Thus the subject-Receiver communicates, as sender, knowledge about its own performances. 3. Often posited as belonging to the transcendent universe, the Sender is the one which communicates to the subject-Receiver (belonging to the immanent universe) not only the elements of modal competence, but also the set of values at stake. The Sender receives the communication concerning the results of the subject-Receiver’s performance; it falls to the Sender to sanction this performance. From this point of view and in the framework of the narrative schema, the **manipulatory Sender** (the initial Sender) can be opposed to the **judiciary Sender** (the final Sender)” (Greimas and Courtés 1979, pp.293-294).

⁹⁵ “In the very general sense, **contract** can be understood as the fact of establishing, of “contracting” an intersubjective relationship which has as its effect the modification of the status (being and/or seeming) of each of the subjects involved. Even though this intuitive notion cannot be defined rigorously, we need nevertheless to posit the term contract so as to determine progressively what are the minimal conditions under which the establishment of “entering into a contract” between two subjects takes place. These conditions can be viewed as being presupposed by the establishment of the structure of semiotic communication. It is indeed necessary to recognize, hidden under the contract, this “phatic communication” which constitutes the necessary and preliminary undergirding for any communication and which seems to involve both a tension (a well-disposed or a mistrustful expectation) and a relaxing (as a kind of response to the expectation). Indeed, the establishment of the intersubjective structure is at once, on the one hand, an opening toward the future and toward possibilities for action and, on the other hand, a constraint which somehow limits the freedom of each of the subjects. We propose to use the term **implicit contract** to designate this set of preliminary components on which the intersubjective structure is based” (Greimas and Courtés 1979, p.59).

⁹⁶ “The sender normally occupies the positions of mandatory sender and of sender-adjudicator. At the beginning of a narrative programme, the sender establishes a contract with the future subject and instigates the system of values in accordance with which the subject must act. The sender here is sometimes referred to as the mandatory sender to distinguish it from the later role of sender-adjudicator. The latter is the sender who intervenes at the stage of sanction or the glorifying test. At this point the performance of the subject is being judged with regard to the original mandate [...] The roles of mandatory sender and of sender-adjudicator, however, are not always held by the same actor” (Martin and Ringham 2000, p.122).

attempt to act. Equally, the participants' inability to act is not sanctioned. The participants have failed to bring about the transformation in relation to the object required of a subject of doing and, consequently, the subject that this transformation would usually construct does not eventuate. This undermines the participants' access, during illness, to the form of self established through the role of the subject of doing where either the participants are both sender and receiver or where the sender is another party. Where the sender is another party, the participants' ability to participate as a subject of doing in relationship is also undermined.

Assuming that action can be understood in these terms, the conclusion to be drawn here is that receiving a mandate to act is necessary but not sufficient to establish a subject of doing and, where the sender is either the receiver or another party, the establishment of the receiver as a subject of doing is dependent on receiving sanction. The process of transaction is not complete until the action is sanctioned as complete through a glorifying test⁹⁷. It is only when action has been sanctioned, by the sender-adjudicator and the contract and transformation therefore witnessed as complete, that a subject of doing comes into being.

An inability to act undermines the participants' ability during illness to become a subject of doing, most especially where this requires connection with another party. It does so because the participants do not have access to sanctioned action, without which transactions do not complete and consequently the subjectivity established through the role of subject of doing is not brought into being. Instead of becoming a subject of doing, the participants experience a subjecthood left suspended, neither receiver⁹⁸ nor subject. In their contemporaneous accounts, the ill participants describe experiencing this lack of subjecthood as loss culminating in grief. Where the participants fail to receive sanction from another party, they describe this as resulting in a sense of isolation and disconnection, "you're isolated from your own family", which is in itself a further grief. This represents an absence of an intersubjectively or socially sanctioned self. Both this absence and the absence of an internally sanctioned self contribute to an overall disintegration of self which participants describe as "a psychological loss" and a consequent "loss of world".

⁹⁷ "A discursive figure linked to the narrative schema, the **glorifying test** is situated in the cognitive dimension; such is not the case for the qualifying and the decisive (or main) tests, which it presupposes. It appears in the narrative when the decisive test has been carried out in the secret mode. As a cognitive performance (and persuasive doing) of the subject, it call for-on the corresponding plane of competence-a *being-able-to-cause-to-know* figurativized by the mark. As the sender's cognitive sanction, within the contractual component of the narrative schema, it is the equivalent of recognition" (Greimas and Courtés 1979, p.137).

⁹⁸ "1. In information theory, the **receiver** (as opposed to the sender) designates the domain in the process of communication where the message is received. In this sense the receiver is not necessarily the one to which the message finally must be transmitted. 2. In semiotics, and for any type of communication (verbal or non-verbal), the term addressee (taken from R. Jakobson) is used with a comparable meaning. In the particular case of verbal communication, the receiver (to which can be linked the concepts of reader and listener) will be called enunciate. 3. Beyond the simple question of terminology, the difference between communication theory and the semiotic point of view resides, in the first case, in that the receiver represents an empty position (this is consistent with a mechanistic perspective), whereas, in the second case, the addressee corresponds to a subject endowed with competence and apprehended at a given moment of its becoming, in a more "dynamic" perspective (this underlines the more "humanist" point of view adopted in semiotics)" (Greimas and Courtés 1979, p.256).

There is one further dimension to this situation that the participants relate. Some of the ill participants *directly* described a sense of loss with respect to the ability to “act”, “do” and be “able” and related a conflict or “battle” that arose in relation to this loss of ability to do.

I18: There's a battle going on about what I should be doing and what I can do. I should be able to do this but my body's telling me I can't. That's a biggie for me. I have to really tell myself that I have an illness, you know, that there is a reason. There's a reason why I can't do it and it's okay.

In many cases this conflict became an impediment to the ill participants' ability to sanction the “rest” they perceived they needed. The need to rest contradicted the ill participants' need to establish their subjectivity through doing. It reinforced the participants' grief over their loss of ability to do. This lack of access to the ‘subject of doing’ in combination with the indefinability of the illness (see section 8.2) and the ambiguity of self health (see section 9.4.2) arguably leads to a situation where, in illness, the participants are unable to establish either an inner or outer ground for the self (see section 4.13). It is as if the participants are left facing the Cartesian Anxiety (see section 4.13).

The indefinable nature of the illness and its unpredictability contributes significantly to this disintegration of self and arising from this self disintegration the participants describe experiences of “confusion” and “sadness”. This “sadness” is distinct from the participants' descriptions of “loss” or “grief” in the sense that it is an even more static state: it does not come and go or accumulate over time. The “confusion” the participants describe is similarly static. Despite the fact that the participants enlist the lexeme “sadness”, within the ‘having an illness self’ narrative both sadness and confusion are also unusually aphoric and atemporal, as if such moments become suspended in an emotionless, timeless space.

On the rare occasions that the participants made direct reference to the effect of having CFS on their sense of self, they described the illness as “shattering” and “absolutely destroying” any sense of self. A few participants spoke of this disintegration or “destruction” of self as “soul destroying” and considered it to be a “personal failure”. “I feel like I’ve had an atomic bomb dropped on my life” one participant commented. Looking from the perspective of the discourse on CFS as a whole, it would seem that the unbounded, all-pervasive and all-consuming aspects of the illness experience (see section 8.2) and specifically the exhaustion, weakness, numbness, pain, anxiety, panic, memory, communication and other cognitive problems the participants describe (see section 8.4), contribute significantly to this disintegration of self, even in cases where participants had experience in adapting to impairment through their experience of a previous or a concomitant condition.

9.9 Analysis

9.9.1 The ‘Self Before Illness’: Craving After Permanence and Continuity

The ‘self before illness’ (see section 9.2) initially appears to be acutely aware of form, the first aggregate. Its emphasis on the pragmatic dimension, reflected in the narratives’ preponderance of the subject of doing, however, shows that this self narrative is a retrospective account of the ways in which the participants believe they manipulated ‘outer reality’ prior to illness. Absent from the ‘self before illness’ is any account of the proprioceptive⁹⁹ aspects of form. In phenomenological terms, this self demonstrates awareness of the psyche’s motivation of action but lacks awareness of somatic contribution to action.

The semiotic analysis suggests that the ‘self before illness’ narrative largely lacks a thymic dimension as this narrative does not express significant euphoria, dysphoria or aphoria. Within the aggregates, the equivalent to the thymic dimension is the second aggregate, pleasant, unpleasant or neutral mental or bodily feelings and sensations. The semiotic analysis therefore suggests that the second aggregate is underrepresented in the ‘self before illness’ narrative.

Desire, anger and ignoring are the components of impulse, which, along with perceptions, are represented by the third aggregate. Desire, anger and ignoring are also described as the three poisons (Varela, Thompson, and Rosch 1991, p.67): once present, they lead to further grasping. In the ‘self before illness’ narrative, impulse is present in the form of the participants’ desire or impulse ‘to do’. This impulse ‘to do’ is, for instance, clearly represented in the emphasis on drive in the quotation from participant 21 (see section 9.2.1). The strength of this impulse ‘to do’ is evident in the repetitive use of superlatives referring to action throughout the ‘self before illness’ narrative, yet there is no evidence in any of the self narratives considered in this chapter that this impulse ‘to do’ is examined. It is as if this impulse ‘to do’ has become habitual. This is the territory of the fourth aggregate, dispositional formations or habits, motives and emotional tendencies. The formulation and accumulation of such a pattern of habitual action could contribute a basis for the mistaken perception of the permanence of the self as a doer (see section 4.9). Or, in other words, it could contribute the grounds for a mistaken perception of an ego-self.

Of the five omnipresent mental factors, the fifth, attention, appears weak with respect to the second aggregate and it also seems that the ‘self before illness’ does not pay attention to proprioception, particularly the overall state of the body that is ‘inner somatic reality’. In terms of the derivative unwholesome mental factors, this suggests the presence of nondiscernment (*asamprajā*). This lack of attention to both the proprioceptive and affective point towards a lack

⁹⁹ A proprioceptor is “any receptor, as in the gut, blood vessels, muscles, etc., that supplies information about the state of the body” (Makins 1992, p.1072), therefore, proprioception is the sense of bodily state.

of attention to ‘state’. Of the remaining contingent mental factors (Varela, Thompson, and Rosch 1991, p.257), it is noteworthy that the participants retrospectively observe of the ‘self before illness’ that it lacks ‘reflection and investigation’ of the self; it lacks self-consciousness. In contrast, with respect to action, arguably there is an ‘attachment’ to action and an overemphasis on ‘diligence’.

With its focus on ‘outer reality’ and lack of attention to proprioception and affect, this ‘self before illness’ has an uncanny resemblance to the disembodied ‘eye’ of the nineteenth century scientific realist (Varela, Thompson, and Rosch 1991, p.4). The disembodied ‘eye’ is made possible only through an equally disembodied ‘I’, the assumption that the ‘I’ of the mind can be located distinctly from the matter of the body (see section 4.6). This mind/body dichotomy leads to the Cartesian Anxiety, the search for an external ground, whether it is the outer ground of the realist conception of the world or the inner ground of the idealist conception of the mind (see section 4.13). One such form of searching is the grasping after an inner ground or subject in the form of an ego-self (see section 4.13). Such an ego-self is characterised by the illusion of self coherence (see section 4.9) and the belief that the self exists as something singular, independent, essential and ‘truly’ existing (see section 4.7). Constructing or grasping after such a self is observed to be the source of dukkha or suffering (Varela, Thompson, and Rosch 1991, p.61). Both Buddhism (see section 4.9) and cognitive science (Tsakiris and Haggard 2005) have demonstrated that the self is fragmented, it is not unified and therefore conclude that the ego-self is an illusion (see section 4.7). The participants present the ‘self before illness’ as atemporal, certain, permanent and static (see section 9.2.1). The ‘self before illness’ is not engaged with any processes of transformation (see section 9.2.1). These immanent structures within the ‘self before illness’ point towards the assumption that the self is somehow singular, independent, essential and ‘truly’ existing. Equally the immanent structures of consistency and coherence, particularly in reference to the ability to do (see section 9.2.1), point toward a self based on the illusion of the coherence of the self (see section 4.9). That the participants crave or grasp after these aspects of the ‘self before illness’ is evidenced within this self by the extent to which these features of the ‘self before illness’ are euphorically described and positively evaluated (see section 9.2.3).

This analysis suggests that the ‘self before illness’ represents a form of ego-self, one that has its origins in a dualism of mind from body and consciousness from affect and proprioception. It is as if the ‘self before illness’ depicts an internalisation of the realist conception of the world. It represents a specific disposition of mind that craves after an outer ground in the form of the ability to do (see section 4.13). Recalling the Buddhist claim that it is precisely because there is no permanent ego-self that experience can arise, that the very permanence of an ego-self

prohibits experience (Varela, Thompson, and Rosch 1991, p.80), the question that arises is just how much experience, including experience of the self, could the ‘self before illness’ experience? Or, in Gallagher and Marcel’s terms (1999), with so much of its attention and intention focused on the outer reality of exteroceptive action, how much of the self, particularly the interoceptive self, could such a self have access to? The context that this self constructs for itself through the imagination and fantasy of operational closure seems to exclude interoceptivity. It becomes important to consider how being fixed on exteroceptive action as an outer ground might limit the fragile ontology and virtuality of the self? In what ways, for instance, would this ground prohibit letting go?

9.9.2 The ‘Self That Becomes Ill’: An Interruption of the Ego-Self

The ‘self that becomes ill’ stands in contrast to the ‘self before illness’ in a number of respects. In contrast to the static, permanent ‘self before illness’, the ‘self that becomes ill’ (see section 9.3) signals the onset of the illness and represents a fundamental transformation of self from health to ‘having an illness’. It is the most significant transformation the ill participants relate and is second only to recovery in the recovered participants’ discourse. This transformation becomes a central hub around which much of the participants’ discourse revolves. It introduces a self that changes. The ‘self that becomes ill’ (see section 9.3) signals the beginning of the illness process. Both this process and this self are experienced as unpredictable. This contrasts directly with the certainty and consistency of the ‘self before illness’. The unpredictability of the illness contributes to the indefinability of the ‘self that becomes ill’. This contrasts with the coherence of the ‘self before illness’.

Most striking in a comparison between these two self narratives is the presence of proprioception in the ‘self that becomes ill’. This self narrative clearly demonstrates that, in their intention to understand the context of the experience of becoming ill, the participants pay attention to proprioception. Basic element analysis suggests that consciousness is constituted by basic elements which are comprised of an experiencer, an object and the relation between the two (Varela, Thompson, and Rosch 1991, p.117-119). Different mental or sensory experiences involve different experiencers. These experiencers are disjoint but contribute to the sense of self. In the ‘self that becomes ill’ (see section 9.3), the participants describe proprioceptive symptomatic phenomena which they identify with the experience of becoming ill. This represents a shift of attention, the presence of intensified interest (*adhimoksa*) with regards to proprioception. The participants describe their symptoms (object and relation) as unfamiliar (see section 9.3). This is consistent with the observation of the ‘self before illness’ (see section 9.2), in which proprioceptive phenomena are not represented. In this respect, the experiencers which

predominantly require conscious attention have changed from a focus on the experiencers of ‘outer’ phenomena to a stronger focus on the experiencers of ‘inner’ phenomena. This analysis suggests that it is the change of focus with regards to experiencers, the need to more strongly pay attention to the experiencers of ‘inner proprioceptive reality’, that disrupts the experience of the ‘self before illness’ as permanent and brings about the experience of a transforming self. This is because the experiencers of ‘inner’ proprioceptive reality have been habitually absent from attention and may contribute to an explanation for the degree to which becoming ill is experienced as an abrupt and extreme incursion.

Transitioning to a self that changes, one that has an unpredictable illness and requires a shift of attention and interest (*adhimoksa*) toward proprioception, contributes to the participants’ experience of the ‘self that becomes ill’ as indefinable and unfamiliar. Such changes would make an ego-self untenable for the participants. Despite the many differences between the ‘self before illness’ and the ‘self that becomes ill’, the later still shares with the former an absence of the thymic dimension, which suggests a common lack of attention to affective aspects of the second aggregate.

9.9.3 ‘Having an Illness Self’: Contemporaneous and Retrospective Accounts.

Regarding the first aggregate, the contemporaneous ‘having an illness self’ (see section 9.5), unlike the ‘self that becomes ill’, but similar to the ‘self before illness’, does not appear to pay attention to proprioception. Consequently there is no evidence that the ill participants are able to access this aspect of self. In their intention to understand the experience of having an illness, this contemporaneous self narrative suggests that the participants do not include proprioception within their reflections on their experiential context. As a chronic unbounded experience (see section 8.2), the participants find perceiving clear parameters to the illness, including a clear point of conclusion to the illness, very difficult. Many of the participants who had been ill for more than six months seem to begin to perceive the state of having an illness as potentially unchanging; it becomes a dispositional formation. Consequently, similar to the ‘self before illness’, the contemporaneous ‘having an illness self’ begins to take on an element of stasis.

The apparent preponderance of the thymic dimension to the contemporaneous ‘having an illness self’ appears to represent a difference between this self narrative and both the ‘self before illness’ and the ‘self that becomes ill’ with respect to the second aggregate. Although monotonic and repetitive in style, the contemporaneous ‘having an illness self’ is, nonetheless, presented as a feeling self. In this respect, the experiencers that the ‘having an illness self’ narrative suggests the participants are paying attention to have changed. This appears similar to the shift in attention discussed with regards to the ‘self that becomes ill’. The ‘having an illness self’ seems

to be paying more attention to the experiencers of the ‘inner’ phenomena of affect. It would appear that the experiencers of ‘inner affective reality’ have been habitually absent from attention within the ‘self before illness’ and the ‘self that becomes ill’. Again, similar to the disruption of the unified experience of self discussed concerning the ‘self that becomes ill’ and the need to pay attention to ‘inner proprioceptive reality’, the change of focus with respect to the experiencers of ‘inner affective reality’ presented by the ‘having an illness self’ causes a disruption to the experience of self. The grief and loss so predominant in the contemporaneous ‘having an illness self’ does not seem to transform the self, however. Equally, this loss and grief do not seem to provide the energising mechanism to transform intention into action. It is as if the ‘having an illness self’ becomes stuck in a permanent state of ambiguity.

In contrast to the contemporaneous account, in the retrospective account of the ‘having an illness self’ (see section 9.6), the self is described as physically “numb” and “immobile”. This shows that the recovered participants are able to access and do pay attention to proprioception in their recollections. It is by paying attention to proprioception that the recovered participants become able to recall this numbness and recognise it as an absence of self. In retrospect, the ‘having an illness self’ is also considered emotionally numb and absent. This contradicts the contemporaneous accounts of the ‘having an illness self’. It brings into question the assumption that the grief of the contemporaneous ‘having an illness self’ is, in fact, an aspect of affect. The recovered participants’ description of the ‘having an illness self’ is not thymically monotonic. It demonstrates a broader attention to the experiencers of ‘inner affective reality’. When the recovered participants access the ‘having an illness self’, they can include affect and proprioception in the experiential context to which they pay attention. There is nothing in the recovered participants’ accounts of the ‘self before illness’ that suggests that, in retrospect, they are not able to include affect and proprioception within the context to which they are paying attention. This might suggest that the ‘self before illness’ narrative, which is consistently related by both the ill and recovered participants is more than just a reflection on the illness experience. It may be the case that, prior to illness, for instance, the participants did not pay adequate attention to affective and proprioceptive experience.

9.9.4 Sanction and Enaction

The commonalities between the contemporaneous and retrospective ‘having an illness self’ narratives are most remarkable with respect to sanction. Both relate to some extent the grief associated with the loss of action and the grief associated with the perceived loss of sanction by others (see sections 9.5.2, 9.8, 8.9 and 8.10). With respect to self sanction, both accounts unanimously describe a loss of trust in the self that leads to a loss of self-esteem and self-

confidence (see sections 9.8 and 9.7). This loss of trust in the self is experienced hand in hand with the indefinable nature of the illness and this combination is described as leading to a “shattering” and “soul destroying” disintegration of self. Both the contemporaneous and retrospective accounts of the ‘having an illness self’ describe this disintegration of self as a personal failure that leads to a sense of confusion and sadness. This is consistent with Marcel’s observation that the self as an agent depends on the reliable efficacy of action and that self-awareness is intrinsic to action.

Marcel ... suggests that immediate awareness and experienced ownership of action go together and lie in the specific ‘trying’ underlain by pre-action specifications. ... This perspectival sense of self as agent is normally set against and supported by a long-term background sense of agency. This latter involves not only awareness that one has intentions but crucially the sense that one’s actions, or rather one’s tryings, are *reliably effective*, i.e., that spontaneous movements do come about in accordance with intentions that conform to the physics of the environment and the body. However, the main point is that the data suggest that self-awareness, experienced as ownership of action, is an intrinsic property of action itself, and is perspectival. (Gallagher and Marcel 1999, p. 292)

Although the ‘having an illness self’ is trying to act, these actions are not experienced as reliably efficacious. This undermines action, the self and, in its ambiguity of neither ill nor healthy, the ability of the ‘having an illness self’ to bring a sense of self to action. It is a potentially permanent state of being that cannot act and cannot not act.

The actantial narrative schema¹⁰⁰ of semiotics provides a framework through which to understand the relationships within the sphere of human action. These relationships include those between the roles of sender and receiver in relation to the object and subject of action. The canonical narrative schema¹⁰¹ extends the actantial narrative schema by defining a standard form for describing how actions take place and are evaluated. The canonical narrative schema is a framework through which the form the participants’ narrative takes with respect to action can be analysed. This schema is composed of receiving the mandate to act (the contract), acquisition of the state of competence¹⁰², performance of the action and receiving sanction for the successful completion of the contract.

¹⁰⁰ The actantial narrative schema is “a fundamental universal narrative structure that underlies all texts. There are six key actantial roles or functions arranged in three sets of binary opposition: subject/object; sender/receiver; helper/opponent. Together the six actants and their organization account for all the possible relationships within a story and indeed within the sphere of human action in general” (Martin and Ringham 2000, p.19).

¹⁰¹ The canonical narrative schema “presents a universal prototype for the structure of narrative. It is composed of three tests: the qualifying test, the decisive test and the glorifying test, which unfold in logical succession. These tests are preceded by the stage of manipulation or contract” (Martin and Ringham 2000, p.32). See also: (Greimas and Courtés 1979, pp.203-206)

¹⁰² “3. The distinction between what competence is and what it bears on (that is, its object, which, in the case of linguistic competence, is identified, once it has been described, with grammar) allows us to consider competence as a modal structure. As is clear, here we return to the whole set of problems concerning act. If act is a “causing-to-be”, competence is “*that* which causes to be”, that is, all the prerequisites and presuppositions which make action possible. Thus if the problem of competence in the (vast, but nonetheless limited) linguistic domain is transposed to that of semiotics, it can be said that every sensible behaviour or every sequence of behavior presupposes, on the one hand, a virtual narrative program and, on the other, a particular competence which makes its carrying out possible. Competence, thus conceived, is a **modal competence** which can be described as a hierarchical organization of modalities (it will be based, for example, on a willing-to-do or a having-to-do, governing a being-

The binding chain of causality, or Wheel of Life, provides an explanation for the causality of mind: that is, how habitual actions form and continue over time (see section 4.9). Comprising twelve links, the Wheel of Life provides a model for the manner in which the aggregates and mental factors come to constitute recurrent patterns within experience. Enaction provides an explanation of the embodiment of cognitive action and the embedding of cognition and experience within a biological, psychological and cultural context (see section 4.14).

By investigating the relationship between the canonical narrative schema and the twelve links of the chain of causality, it becomes possible to identify parallels between the recurrent patterns formed by the aggregates and mental factors and the standard form in which the canonical narrative schema suggests actions take place. The goal of such a synthesis is to become better equipped to identify the ways in which action breaks down for the participants. It is a means through which both the semiotic analysis and the analysis of the data in regards to the aggregates and mental factors can illuminate each other. This, in turn, provides insight with respect to how what the participants report of their experience may point towards specific breakdowns within enactive processes.

Volitional actions (link two) follow from ignorance (link one) as compulsive actions, a ‘having to do’. As such, links one and two are the links in the chain that belong to the stage of contract concerning the acquisition of having to do. Craving and grasping belong to the stage of contract about the acquisition of wanting to do. Links three through seven, consciousness (including intention), the psychophysical complex, the senses, contact and feeling, are the links in the chain that belong to the stage of competence, the acquisition of being-able-to-do and/or knowing how to do. Links ten through twelve, becoming, birth and decay, belong to the stage of performance, the accomplishment of action.

Intention is the omnipresent mental factor that motivates and sustains action. It enters the chain as a result of prior volitional action, is present in consciousness, leaves its trace through links four through seven and affects the outcomes of action by the modification of the relation between craving and grasping.

Sanction could be considered a description of the mechanism by which the results of actions become incorporated into future intention. Although sanction occurs after the performance of action, it becomes part of future actions by informing intention. In Gallagher and Marcel’s terms regarding future action, sanction would lie within intention and occur after performance.

able or a knowing-how-to-do). It must be distinguished from **semantic competence** (in the broadest sense of the word semantic, the one which is used, for example, when it is said that the deep structure of language is logico-semantic in nature) the simplest form of which is the virtual narrative program. Once joined, these two forms of competence constitute what can be called the **subject’s competence**” (Greimas and Courtés 1979, p.45).

Experimental research ... suggests that awareness of one's action is based not so much on actual feedback from movement itself or from peripheral effort associated with such movement, but more on that which precedes action and translates intention into movement – high-level motor commands, experienced as 'tryings'. Further research ... indicates that one's initial awareness of a spontaneous voluntary action is underlain by the motor commands relating to the effectors to be used. That is, although the content of experience is the action, its source is in fact what lies between intention and performance. (Gallagher and Marcel 1999, p. 291)

As the post-facto reinforcement of successful action, sanction becomes a pre-action specification. Sanction is based on the evaluation of the fitness of action. According to the enactive approach, fitness implies the satisfaction of values relative to a proscriptive logic but not necessarily the optimality of action, which would require the evaluation of a prescriptive logic (see section 4.14).

In the enactive approach to cognition, intentionality is the name given to the process by which actions *a priori* or *post facto* fulfil or fail to fulfil the possibilities of action (see section 4.14). As such, intentionality is expressed through the direction of action. This encompasses both intention and sanction. Sanction, therefore, effects modifications to intentionality and, thereby, the configuration of what is seen to be desirable or even possible action. Sanction, intention and their expression in terms of intentionality are all processes by which the organism makes changes to its processes: they are forms of self-modification (Varela, Thompson, and Rosch 1991, p.139).

Both enaction and the semiotics of contract suggest that “without a firm belief in the truthfulness and reliability of the partner the contract cannot become effective” (Varela, Thompson, and Rosch 1991 p.45). Both the retrospective and contemporaneous ‘having an illness self’ relate a sense of loss of self trust and a self disintegration (see section 9.7). This perception of self disintegration is itself a volitional action, one that stems from ignorance. Such a self lacks the ability to hold a firm belief in the truthfulness and reliability of itself and therefore to provide self sanction. It is likely that this would undermine the participants’ ability to enter into contract with themselves. Where this lack of self trust has become habitual, it would also undermine the participants’ ability to enter into contract with others. The participants describe a state of sadness and confusion that results from this sense of self disintegration (see section 9.7). Despite the fact that the participants report sadness and confusion, these aspects of the participants’ narrative still appear to be thymically underdeveloped. It is plausible to suggest that this state and the “grief” reported by the contemporaneous ‘having an illness self’ are in fact not so much expressions of emotion as descriptions of a cognitive absence, a state whereby cognitive actions that may have at some point previously existed have largely ceased to occur.

There is, in the narratives of both the contemporaneous and retrospective ‘having the illness self’, an absence of sense (the fifth link) with regards to perceiving proprioception. This reflects a self that is habitually focused at one end of the psychophysical complex (the fourth link). The contemporaneous ‘having an illness self’ is also limited with respect to feeling (the seventh link). All of these aspects of the ‘having an illness self’ could potentially undermine competence and consequently restrict the participants’ ability to enter into performance.

Within the enactive approach, perception, as one of the components of enaction, is in itself a perceptually guided action (see section 4.14). Is it that an absence of attention to proprioception, as evidenced within the participants’ narratives of self, implies an absence of proprioceptive perception and therefore a breakdown of the enactive process with respect to physiological state? If this is the case, it would be consistent with the participants’ reluctance to rest (see section 9.8). As far as affect can be considered to be physiological, this would also suggest that a lack of attention to proprioception may imply a lack of attention to affect and, as such, would suggest that affect would then be left out of the perceptions that guide action.

All the self narratives discussed in this chapter take as their central concern the participants’ ability or inability to perform or have access to the role of ‘subject of doing’. Following from grasping, the ‘self before illness’ becomes, through external action, a ‘subject of doing’, whereas the ‘self that becomes ill’ and the ‘having an illness self’ are impaired from doing so.

The essence of sanction is that it is a process of the evaluation of the fitness of action. Such evaluation clearly requires that the organism operate criteria and attend to accurate information on which to base evaluation. Such information would include the relevant aspects of the contextualisation of the action under consideration. In enactive terms, this attention process is common sense (see section 4.13). An absence or lack of attention to proprioception and/or affect could lead to an absence of accurate information, that is, a lack of adequate contextualisation and result in inappropriate evaluations.

Inappropriate criteria could arise from beliefs that are not fit for the organism in the sense that they do not cause the processes of enaction to result in viable structural coupling (see section 4.14). As such, inappropriate criteria undermine the viability of the organism; its actions become insufficiently accurate for the environment. In the present context, for the participants, the internalisation of the mind/body dichotomy may be just such a belief that leads to inaccurate criteria. Equally, inappropriate criteria could arise from unrealistic criteria for performance, leading to inappropriate values of sanction. Such inappropriate evaluations would eventually undermine the process of sanction and so affect intention.

The participants report a lack of “understanding” and “comprehension” on the part of others which suggests they experience a lack of external sanction. In addition, in the discussion of contract above, the participants’ lack of self trust leads to a lack of self sanction. This could create the experience of a general absence of sanction. Also, when the participants fail to perform actions, they receive negative evaluation from others and negatively evaluate themselves, which suggests a preponderance of negative evaluation. A history of such a preponderance of negative evaluation and lack of sanction is likely to accumulate and create difficulties in all the internal processes of enaction (sanction, evaluation, contract, competence and performance) because of operational closure (see section 4.13). Cognitive structures (see section 4.14), such as beliefs, develop from the recurrence of sensorimotor patterns (including self evaluation) which arise from and during the performance and guidance of action. Operational closure implies that the effectiveness of this (self modifying) process depends critically on the accuracy of those evaluations (Varela, Thompson, and Rosch 1991, p.140). If these evaluations are excessively negative then they will excessively restrict the organism’s assumptions about the possibilities for action.

The enactive approach concludes that the mind arises from the process of actively coping with the world and the objects of the world are co-arising or co-emerging with the subject’s engagement with them (see section 4.14). If a preponderance of negative evaluations, such as that described above, leads to an excessively restricted sense of the possibilities of action, the organism will be actively engaging with the world to only a limited extent and thereby enacting a limited world. This could explain the participants’ experiences of their world shrinking (see section 8.2).

In the case where an action is a continuous process, enaction takes the form of the continuous initiation, competence, performance and monitoring of the action performed in parallel, where monitoring refers to the sanction and evaluation process. One such example of a continuous process is the narration of experience, such as that related by the participants. The participants’ talk is often consistently disrupted by self interruptions, incomplete sentences, losing track, and repetition. These difficulties in the performance of expression are occurring despite the fact that the performance requested, participation in the interview process, is both pragmatically and socially contextualised. Gallagher and Marcel’s (1999) work suggests that such a context provides the optimum conditions for performance. The difficulties the participants experience in interview performance could be considered direct evidence for the breakdown of continuous enaction. This could also provide a potential approach to developing a diagnostic test

for the disorder. It is interesting to note that it is the loss of the potential for such contextualised actions that the participants describe as a loss of world.

The maintenance of a sense of self is likewise a continuously enacted process. In a situation where the maintenance of a sense of self is compromised, it would be reasonable to expect to see a ‘decay’ in the coherence of the sense of self. The participants describe: “slowly your confidence and self-esteem are just totally eroded”. The participants claim that this erosion of confidence and self-esteem is a consequence of no longer being able to trust in the coherence of their sense of self (see section 9.7). The participants also suggest that having self-esteem would contribute to the ability of an individual to recover. As such, self-esteem represents the perception of a viable or maintainable sense of self.

9.10 Conclusion

The self narratives analysed in this chapter speak of a disruption to the continuity of self that is represented by the ‘self before illness’. This disruption to the efficacious creation of self through action is communicated through absence, either the absence of grief and loss or a conscious awareness of the absence of self. This absence of self, in particular, contrasts with the self naïveté of the ‘self before illness’ and leaves the self facing the unknown. There are also silences in these self narratives, those aspects of self experience that are not expressed and perhaps not consciously experienced. The self narratives related in this chapter are largely emotionally silent and these narratives are almost completely silent with respect to proprioception. The self narratives presented in the next chapter are predominantly about how such absences and silences are negotiated.

10. Recovery and the Self

10.1 Introduction

What is unique to the three narratives of self, the ‘accepting self’, the ‘surrendering self’ and the ‘recovered self’, to be discussed in this chapter is an attention to emotion. To elucidate this aspect of these selves it is necessary to enlist relevant concepts from contemporary emotion theory which are briefly presented in section 10.2. In section 10.3, the semiotic analysis of the ‘accepting self’ is presented. It is the contrast between the ‘accepting self’ (presented most predominantly by the ill participants) and the ‘surrendering self’ and ‘recovered self’ narratives (those self narratives presented almost exclusively by the recovered participants) that demarcates the differences in contribution between the recovered and ill participant subgroups to the discourse on CFS. The ‘surrendering self’ and the ‘recovered self’ represent aspects of the experience of CFS that are largely only available to those who have recovered. The semiotic analysis of the ‘surrendering self’ and ‘recovered self’ narratives are presented in sections 10.4. and 10.5 respectively. The self narratives presented in this chapter are analysed from an enactive perspective in section 10.6. This analysis also reflects back on the self narratives discussed in chapter 9. Toward this end, the role of existential feelings and goal obstruction within all the self narratives expressed by the participants are discussed in subsections 10.6.4 and 10.6.5 respectively. The chapter is concluded in section 10.7.

10.2 Emotion Theory

Several authors are calling for a taxonomy and classificatory system for emotions (Panksepp 2005; Watt 2005). Others are employing cross-cultural studies and drawing from Eastern traditions for the contributions that these approaches can make to an understanding of feeling and emotion and, particularly, to determine what can be defined as an emotion (Georges 2002). Numerous theorists are concerned with the embodied nature of emotion (Mazis 1993; Panksepp 2005). Just as philosophers and scientists alike are examining the neurological basis of consciousness (Cosmelli et al. 2004; Cosmelli, Lachaux, and Thompson 2007, forthcoming; Metzinger 2000; Noë and Thompson 2004, 2004; Thompson and Varela 2001; Varela 1995; Varela et al. 2001), David Rudrauf and Antonio Damasio (2005) are employing a neurophenomenological approach to the investigation of emotion and others are examining its neurological and biological aspects (Panksepp 2005). Prinz (2005) argues that emotions are interoceptive, bodily states of change that become ‘felt’ or have bodily phenomenology when conscious attention is brought to them.

Any account of emotional consciousness should be an account of how we come to have conscious experiences of bodily changes. On this view emotions are perceptions of the body, and conscious emotions are conscious perceptions. (Prinz 2005, p.21)

Unconscious emotions are those that are not ‘felt’; attention has not been directed toward them. The act of feeling an emotion and its conscious phenomenological perception are not distinct, they are modulated by attention. Prinz (2005, p.23) suggests that emotional perception is not unique, rather, it is consistent with other perceptual states.

Lewis and Todd (2005) present a ‘neuropsychological timeline’ in which they propose that attention only turns to emotion when plans for action have been persistently obstructed: “we suggest that prefrontal activities greatly extend intentional states while focal attention integrates emotional awareness and goal pursuit in a comprehensive sense of the self in the world” (Lewis and Todd 2005, p.210).

Lewis and Todd (2005) propose three levels of goal obstruction and describe the psychological, cognitive and neurological activity that accompanies each level. Most pertinent for the current research is what they describe as the third level of goal obstruction.

The third level of goal obstruction is designated by changes in the internal milieu rather than changes in the world, but it follows upon the failure (either actual or anticipated) of intended actions to achieve desired outcomes. If one’s goal is to escape an impending threat, then the continued failure to reach a safe haven amplifies feelings of fear and anxiety until they cannot be ignored. ... In all of these examples, it is either intensity or unexpected change in emotional feeling that brings it into focal awareness. (Lewis and Todd 2005, p.229)

Colombetti and Thompson (forthcoming, pp.3-6) review the history of emotion theory and argue that Classical pre-Jamesian theories of emotion, such as those put forward by Aristotle, Descartes, Spinoza and Hume, all acknowledged the psychosomatic nature of emotion. Colombetti and Thompson (forthcoming, pp.6-16) suggest two main reasons why emotion theory ‘lost’ the body and review the work of a number of contemporary theorists who are attempting to re-embody emotion.

In earlier work, Colombetti (2003) argues that successful functioning in the world emerges out of the continual, reciprocal influence of emotion, cognition and somatic response, all of which arise simultaneously and are causally interdependent. Concepts from dynamic systems theory, such as circular causation, collective action, self-organisation and emergent phenomena with their constraining influence on a system, are necessary to understand complex phenomena such as emotion. Through these conceptual tools, dynamic systems theory undermines dichotomies such as knowing versus doing, perceiving versus moving and internal structure versus external expression. Emotion is “a complex process constructed upon the interactions and local feedback of many components, none of which is the leader ... the cognitive (or evaluative)

and the emotive moments are not separated, nor sequentially ordered. They are part and parcel of the same organic activity unfolding in time” (Colombetti 2003, p.10).

From an enactive perspective Colombetti (forthcoming, a) argues that emotion is a whole organism experience. The generation of meaning and sense making are equally environmentally situated whole organism events that enlist emotion and the body, not just cognitive-evaluative processes. Colombetti provides an enactive characterisation of emotion as “the capacity that we share with other living systems to make sense of our environment in virtue of our being self-organizing and adaptive organisms. This is a broader conception of emotion, according to which fear, anger, happiness, guilt, anguish, etc. are only *some* of the many ways in which sense-making manifests itself in experience and in the body” (Colombetti forthcoming, a, p.9). As Colombetti highlights, autopoiesis “places the conditions of possibility of meaning in the processes of self-generation and adaptivity that define living organisms and that, in the simple ones, constitute a primordial form of bodily cognitive-emotional understanding” (Colombetti forthcoming, a, p.10). Ratcliffe’s (2005) ‘existential feelings’ sit well with this broader conceptualisation of emotion. The analysis of the self narratives presented in this chapter will draw upon Lewis and Todd (2005), Ratcliffe (2005) and the enactive conception of emotion developed by Colombetti and Thompson (Colombetti 2003, 2005, forthcoming, a, forthcoming, b; Colombetti and Thompson 2005; Colombetti and Thompson forthcoming; Colombetti and Thompson forthcoming, a). In their enactive characterisation of emotion, Colombetti (2005) highlights the role of valence and Colombetti and Thompson (Colombetti forthcoming, b; Colombetti and Thompson forthcoming, a) pay particular attention to appraisal as an aspect of emotion.

Colombetti (2005, pp.106-14) provides a review of valence in contemporary emotion theory and states: “the notion of valence is used in emotion science to refer to the positive and negative character of emotions and/or their aspects, such as feelings, behaviour, appraisal, etc.” (forthcoming, a, p.22). She considers this dichotomisation of positive and negative emotions too simplistic and suggests instead a multidimensional approach to valence, one that would allow for nuance, ambivalence and the simultaneous experience of opposites (forthcoming, a, p.23). Mathematising phenomenology would reveal the shape of the space of emotion. Suggestions with respect to how phenomenology might be mathematised are discussed in section 12.5. Colombetti (2005, pp.114-5) also stresses the need to avoid conflating emotions and associated behaviours that are similarly valenced.

Colombetti and Thompson suggest that “emotion is a kind of evaluation, and appraisal is part of emotion” (forthcoming, p.21). Appraisals are feelings of appraisal that are constitutive of

emotional experience. In other words, appraisal and emotion are constitutively interdependent, “they form an integrated and self-organizing emotion-appraisal state, an ‘emotional interpretation’” (Colombetti and Thompson forthcoming, a, p.1). Colombetti and Thompson argue that “emotions are simultaneously bodily and cognitive-evaluative: they convey meaning and personal significance as bodily meaning and significance (forthcoming, p.29). The authors comment: “we suspect that there may be no appraisal constituent that is not also an emotion constituent, and vice versa” (Colombetti and Thompson forthcoming, a, p.2).

In developing an enactive approach to appraisal, Colombetti (forthcoming, b) draws on the work of Lewis and Patocka. According to Colombetti, Patocka’s work offers enaction a conception of personhood that emerges out of a lived effortful corporeality, an ‘I’ that is necessarily a movement-orientated embodied agent. Patocka contends that this sensorimotor agent is also affective.

Likewise, for Patocka what characterizes the I is “the primordial phenomenon of effort” (1998, p25). My awareness of having certain possibilities of movement cannot be reduced – Patocka argues – to sensory impressions; it does not depend on external objects. Rather, it is something that points directly to my experience of being an active I, of being the source of movement. This sense of activity is the one that illustrates the I as necessarily corporeal; there cannot be a sense of effort without a body: “the I is possible *only as corporeal* – the I is a willing, striving I and, *consequently*, a corporeal one” (ibid.). Corporeity and sense of effort are thus central to Patocka’s characterization of the lived body and of personhood. A person is an embodied agent that is aware of its possibilities of doing something on its own; the I is an ‘I can’. Moreover – and this is Patocka’s most original contribution – this embodied and practical I is also a feeling affective I: ‘[h]ow we are includes an entire scale of feelings and emotions’ (Patocka 1998, p.78). The sensorimotor dimension of embodiment is thus intrinsically also an affective dimension. (Colombetti forthcoming, b, p.6)

According to Colombetti (forthcoming, b), Lewis provides the neurological arguments that compliment Patocka’s active, embodied affective I.

If, on the one hand, Lewis’s account is thus ‘quasi-enactive’, on the other hand it makes a crucial contribution to the enactive approach – namely, it provides neurological arguments in support of the idea that sensorimotor processes are emotional and evaluative, or rather emotional-evaluative. In an emotional interpretation, perception and action orientation are in a relation of constitutive interdependence with evaluation, arousal and feelings (among others); in short, sensorimotor activity is ‘hot’. (Colombetti forthcoming, b, p.17)

What this implies for enaction is that appraisal is active, constitutively embodied and emotional. As Colombetti comments in earlier work, “the key move is to deny that action is the output of a process in which, first, an object is perceived and, second, it is appraised. If it is required to follow a sequential order, the relation between appraisal and action will remain a contingent one and will never be able to account for the peculiar role of bodily responses in emotions” (2003, p.16). Such an enactive I “has a *direct* experience of its corporeity, and this direct experience of one’s corporeity includes an experience of one’s corporeity in relation to one’s environment”

(Colombetti forthcoming, b, p.19). This also implies that “the lived body is also part of the structure of every appraising experience”; enactive appraisal is “one’s understanding of the surrounding world through, and as, one’s bodily experience” (Colombetti forthcoming, b, p.19). As operational closure would suggest, appraisal and emotion shape our physiology as much as embodiment shapes those appraisals. In Colombetti’s words: “[n]ot only then ‘the first impression of the world is a physiognomic impression’, but perhaps it is also our varied physiognomy that allows us different impressions of the world” (Colombetti forthcoming, b, p.20).

10.3 The ‘Accepting Self’

Having an illness implies a relation to illness. When the majority of the ill participants expressed how they negotiated their relationship to CFS, the principal isotopy that emerged was a need to “accept”, “acknowledge” or “accommodate” the illness. This acceptance isotopy underpins a narrative of self, the ‘accepting self’ narrative, which is almost completely absent from the recovered participants’ discourse. In the ill participants’ reports of their experience, the ‘accepting self’ narrative most often follows the contemporaneous ‘having an illness’ narrative and is frequently interwoven with it. The ‘accepting self’ narrative was the principal narrative related by a large number of the participants who had been ill for more than two years.

I13: Once I'd turned a corner I'd accepted it and decided that I wasn't going to fight it anymore, I just decided to get on with my life. Prior to that, if someone had said do x, y, z, I mean I would've done it, if it had been the cure, I would've done anything for the cure. But the cure will come along. I'm not that fazed about it now. It will happen and when it does, great! I'll be first in line.

In the ‘accepting self’ narrative, “to fight” “it” is held in opposition to “accepting” “it”. In this first sentence, “it” refers to the illness and, more specifically, the inability to act. Statements such as “prior to that if someone had said do ...”, where “that” refers to acceptance, demonstrate that acceptance is directly opposed to action. Fighting “it”, therefore, represents a refusal to “accept” or “acknowledge” the inability to act, whereas acceptance involves accepting the inability to act. It is a means by which the participants “acknowledge” or interoceptively sanction the experience of not-being-able-to-do. For the modal structure of being-able with respect to action, therefore, the compulsion of “fighting” represents the submissive¹⁰³ position not-being-able-not-to-do. “Acceptance” thus becomes the position of independence, being-able-not-to-do. “It”, or “having an illness”, represents the powerlessness of not-being-able-to-do whereas the freedom of being-able-to-do is represented by “health”. Being healthy is the object of desire. Given that the

¹⁰³ In this section, the terms **independence** and **submission** are used in their technical sense as relating to relationships within the semiotic square for being-able. See: (Greimas and Courtés 1979, p.23-4).

participants believe that the position of illness is not available to them, the position of not-being-able-to-do cannot be adopted (see section 9.4.2). To resolve this paradox, the interoceptive action of acceptance requires the renunciation¹⁰⁴ of the object of desire, being-able-to-do. This gesture of renunciation is the defining characteristic of the ‘accepting self’ narrative and it is this renunciation of the object that, in their retrospective accounts of “surrender”, the recovered participants actively refuse to accept. Resolving the inability to do is the principal intention expressed by the ‘accepting self’.

It is noteworthy that, although it is not consciously acknowledged as such, acceptance is a complex interoceptive action, an internal being-able-to-do. The process of this being-able-to-do and the transformation that it implies are referred to metaphorically: “I’d turned a corner”. Unlike the ‘having an illness self’ which chooses exteroceptive action as its focus, the ‘accepting self’ consciously narrates the use of complex interoceptive action leading to a transformation of state.

The ill participants describe acceptance as the “best approach” they “know” given their “situation”. To accept the illness, they need to “be patient”, “learn to laugh” and try not to “get depressed”. Several participants commented that they believed they had “no other choice”. All of these statements and phrases, such as “get on with my life”, “the cure will come along” and “not that fazed”, in the passage above illustrate the degree of passivity and fatalism the ill participants experience in acceptance. As such, renouncing being-able-to-do has not provided the participants with a complete sense of independence in relation to the freedom of being-able-to-do. Rather, it leaves the participants in an ambiguous position more akin to the submission or powerlessness connoted by not-being-able-not-to-do or not-being-able-to-do. Although many of the ill participants convey this apparent lack of choice in regards to action, they expressed the ‘accepting self’ with euphoria and stated strongly that acceptance was not the same as “resignation” or “giving up”. The following comment conveys the precarious process of negotiation coming to “a place of acceptance” involved.

BH: Giving in is not giving up?

I11: Yes, absolutely critical for understanding acceptance as far as I’m concerned. It would be counter-productive for me to stay in denial and try to work through it. I return to the expression ‘soldier on’. I can give in, i.e. acknowledge the fact that I have this right now, but that doesn’t mean, for me anyway, that I’m giving up, that I think that it’s never going to be cured, that I am going to stay as I am or get worse. I’m not relinquishing hope and I’m not relinquishing control. I’m just acknowledging that this is where I am right now.

¹⁰⁴ “Located at the figurative level, **renunciation** characterizes the position of the subject of an utterance of state when it deprives itself of the object of value. It corresponds therefore to the reflexive disjunction of the object of value, effected at any moment whatsoever of the narrative trajectory. With dispossession, renunciation is one of the two forms of privation which can be considered, by virtue of the consequence, as sub-components of the test” (Greimas and Courtés 1979, p.262).

Here “giving in” and “soldier on” denote the position of acceptance and “denial” denotes the position of “fighting”. This establishes the renunciation of the object. Phrases such as “that doesn’t mean ... that I’m giving up, that I think that it’s never going to be cured”, however, clearly communicate that this renunciation does not imply that the ill participants are “relinquishing” or becoming dispossessed¹⁰⁵ of the object of desire. Although the participants renounce being-able-to-do, they believe they are denied access to and refuse the opposite position, not-being-able-to-do. The passive position of renunciation continues to enable the participants to grasp at the object of desire just as they continue to grasp at “hope” and “control”. Renunciation also facilitates the “self-acceptance” of a self that acknowledges that it does not have the same capacity to do as that described of the ‘self before illness’ (see section 9.2).

“I have this right now” is a chrononym¹⁰⁶ that designates the present moment as a distinct period of time in which the “it” exists for the participant. This introduces a degree of temporality to the ‘accepting self’. The present moment provides the participants with a degree of leverage with respect to the potentially endless chronicity of the illness. To this degree, the ‘accepting self’ stands in contradiction to the atemporality of the contemporaneous ‘having an illness self’ (see section 9.5).

The ‘accepting self’ is the most abstract self narrative presented by the ill participants. This self is consciously narrating paying attention to interoceptive context. To the extent that the gesture of acceptance narrates a complex interoceptive action, the ‘accepting self’ does convey a degree of transformation. The ‘accepting self’ is emphatically expressed with euphoria and this gives the narrative a stronger thymic dimension than any other self presented by the ill participants. It also demonstrates that the ‘accepting self’ is paying attention to emotion. This thymic dimension remains monotonic in its valence. The ‘accepting self’ is similarly monotonic in its pragmatic dimension, presenting only one relation to action, being-able-not-to-do. Overall, the ‘accepting self’ conveys a state of considerable stasis.

10.3.1 The Accepting Self and Recovery

Striking, unique and almost ubiquitous to the ‘accepting self’ narrative was the difficulty this self faces in prospectively imagining the recovery process or a recovered self. Participants whose principal narrative was the ‘accepting self’ narrative stated that they could not “imagine” “how”

¹⁰⁵ “Located on the figurative level, **dispossession** represents the situation of the subject of an utterance of state when that subject is deprived of the object of value by a subject of doing other than itself. Thus it corresponds to a transitive disjunction from the object, taking place at any point in the narrative trajectory. Together with renunciation, dispossession is one of the two possible forms of deprivation, which can be viewed, taken as consequence, as sub-components of a test” (Greimas and Courtés 1979, p.91).

¹⁰⁶ “Certain semioticians (G Combet) have proposed to introduce alongside toponym and anthroponym the term **chrononym** to designate specific lengths of time, such as “day”, “spring”, “coffee break”. This word can advantageously replace that of “period”. Together with anthroponyms, chrononyms help to establish a historical anchoring which aims at constituting the simulacrum of an external referent and to produce the meaning effect “reality”” (Greimas and Courtés 1979, p.29).

they would recover or what “kind of person” they would be had they recovered. Even when probed and questioned directly participants did not narrate any recovering or recovered self; instead the related an inability to do so.

I20: I can't imagine good health. I see people out there with good health because they couldn't do the things they do without it, but I can't imagine it.

The repetition of the absolute “can't” shows the extent to which this process of imagining is experienced as inaccessible. This lack of prospective imagining demonstrates an important limitation to the transformative potential of the ‘accepting self’. It is possible that imagining recovery contradicts the principal intention of the ‘accepting self’: resolving the inability to do. It may also suggest the extent to which the ‘accepting self’ finds complex ‘interoceptive’ actions challenging.

That the ‘accepting self’ lacks an ability to imagine recovery contrasts this narrative with the most common way the recovered participants retrospectively describe the inchoation of their recovery process as one that requires a “focus on wellness”.

I23: When I started working full time, I made a commitment to myself to believe that I was well, that the illness had passed, and focus on wellness, wellness, wellness, step into the light, and I just really was focusing on that, and still, every day, I maintain that wellness.

“Focus” represents a process of imagining. It is one of several interoceptive processes narrated by the ‘surrendering self’. “Focusing on wellness” suggests the degree to which the recovered participants enlist interoceptive action in the process of recovery. Although the ‘accepting self’ begins to more consciously observe interoceptive actions than any of the self narratives previously discussed, the descriptions of interoceptive action offered by the ‘accepting self’ seem less nuanced than those of the ‘surrendering self’ and the ‘recovered self’. Those aspects of interoceptive context to which the ‘accepting self’ pays attention seem limited in breadth and depth.

10.3.2 Reassessing Personal Expectations and Goals

Also significant to the ‘accepting self’ narrative is the way in which this self consciously reassesses personal “expectations” and “goals”.

I14: When I realised that I'd put dates on things, that I would be better by Christmas, that I would be better by my birthday, what would happen was I'd have such bad depression afterwards. It hadn't happened for me so I'd be depressed for weeks, and on my birthday, and on Christmas. I'd set times that were obviously significant and I thought, ‘this is doing my head in’. That timeline on things, I was going on huge downs on it because I was trying to put a timeline on it. I don't have one now.

Almost all of the participants who narrated the 'accepting self' placed considerable emphasis on the importance of avoiding setting dates by which goals would be achieved. These participants placed considerably less emphasis on reassessing the goal itself.

"What I did", "when I realised", "I'd set times" and "I was going on" like "I turned a corner" narrate interoceptive action. The numerous references to "depression" and the phrase "and I thought, 'this is doing my head in'" narrate the process of recognising and reflecting on states of affect and communicate the impact of these affective states on the self. Furthermore, the participants are here narrating exercising choice with respect to possible interoceptive actions. Consistent with its principal intention, by choosing to reassess goals and expectations the 'accepting self' avoids interoceptive conflict with the inability to do.

The inability to imagine recovery and the process of reassessing expectations and goals are importantly related in this 'accepting self' narrative. When asked to "imagine" her recovered self, one ill participant commented:

I18: It's as though that person is just out of reach. There is always something coming in and knocking it down ... health-wise ... with the fluctuations of the illness. You're up one day, down the next, and you just tend to learn to go with the flow and accept what's there. Otherwise you'd just end up an absolute psychological mess.

This passage demonstrates the connection made by the 'accepting self' between the unpredictable "fluctuations of the illness" and the consequent perceived need to "go with the flow" in order to avoid ending up "an absolute psychological mess". In this passage, "accept what's there" refers to the ability to act, to meet goals in a way that is consistent with the participants' self-expectations. Acceptance, here expressed as the need to "go with the flow", appears to provide the participants with some leverage on the undefined character of the illness. What this costs is the ability to imagine anything other than going with the flow, including actively participating in recovery. The relative atemporality of "going with the flow" remains the most predominant aspect of the temporal dimension of the 'accepting self' narrative. As with the need to avoid placing dates on achieving personal expectations and goals, "going with the flow" is enlisted by the 'accepting self' as a means to avoid "losing control" of emotion. "Going with the flow" demonstrates the potential emotional dangers the participants avoid by not imagining a recovered self.

10.3.3 Human-Doing or Human-Being

Alongside reassessing goals and expectations, the 'accepting self' articulates a process of reassessing "self-worth". The principal isotopy that emerges around self-worth is 'value'. 'Value' is also the object of value. The 'accepting self' enlists self-value to positively evaluate what the participants "are" or can "be" in opposition to what they "do" or "achieve". This shift

of emphasis from “doing” to “being” is most clearly articulated by several participants when they described themselves as “human-beings” rather than “human-doings”.

I26: I based a lot of my self-worth on the things I did, on my achievements. I guess, slowly, over the years, I've learned to believe I'm valuable for being, not just for doing. There are little things, like people have said to me at different times, that if we were meant to do all the time we would have been called human-doings. So little things like that help me to remember the real learning about accepting myself how I am a lot.

The complex interoceptive process of assessment implied by this gesture of valuing is here reflected in the phrases “I based”, “slowly, over the years, I’ve learned”, “help me to remember” and “real learning”. Moving from deriving self-value from doing to being is described as a slow process that requires the critical assessment of belief, the recalling of interoceptive actions and “learning”. These gestures all connote coordinated interoceptive action. The lexeme “real” suggests the depth of this process whereas references to “time” suggest its breadth rather than temporality.

In changing the way the self is valued, the ‘accepting self’ narrative demonstrates awareness that, historically, self-worth was based on “the things” the participants “did”. This habit or dispositional formation was most clearly represented by the glorification of the ‘self before illness’. The importance the ‘having an illness self’ places on sanction may provide an explanation for how the self came to be valued for doing in the first place (see section 9.8). The preceding passages bring into question the act of valuing the self according to any criteria. That the self *can* be given value is not questioned by the ‘accepting self’.

In the passage above, “others” are enlisted in support of valuing the self for its qualities of “being”. More commonly, however, the participants speak of others in terms of their perception that others value the “doing” self at the cost of the “being” self.

I5: In today’s society, you are judged on what you do instead of even the sort of person that you are ... I had to pick my self-esteem up a bit to think I was valuable enough just to be and to realise that I have got qualities that are valuable.

The “qualities” of “being” that the ‘accepting self’ narrates “learning” to value include aspects of personality, giving and sharing, honesty, integrity and nurturing.

The human-being of the ‘accepting self’ is an expression of being-able-to-be. Within the modal structure of being-able-to-be, the ‘accepting self’ narrative places human-being in contradiction to human-doing as an expression of not-being-able-to-be. Nowhere in the ‘accepting self’ narrative are the positions of being-able-not-to-be or not-being-able-to-be articulated. Nonetheless, it is the focus on being as opposed to doing that distinguishes the ‘accepting self’ from the ‘having an illness self’. This almost exclusive focus on being strongly polarises the ‘accepting self’ and the ‘self before illness’ narratives.

10.4 The 'Surrendering Self'

In contrast to the ill participants, when the recovered participants described their relation to CFS, almost without exception, they retrospectively narrated a 'surrendering self'. This 'surrendering self' chooses to undergo a process of surrendering to the illness.

I23: The most fundamental thing to start was to surrender. I let go and it's scary. One day I was just walking along and it suddenly came to me what I needed to do. I saw this huge big, like a Samurai Warrior standing before me and that was M.E. And it had all its armour and the glittering swords and I realised if I tried to fight it, it would just set me up, I would die. If I surrendered to it, it would just completely vanish and let go and dissolve; the energy that I was feeding it was no longer there. It would just fall to pieces and then once that happened I knew I was just a naked soul and I had to learn soul inspiration, to re-build as my soul wanted me to be this lifetime. Because I've always been a fighter and in Western culture, we always admire fighters. You've got to fight this. You don't, you give way to it. It's not like surrender as in give up, take to your bed and never get out of it. It's give way, just let it go, let it pass by, don't resist it, don't battle with it, just give way. So essential.

Almost unanimously, the recovered participants described actively surrendering and "focusing on wellness" as "fundamental" to the "start" of their recovery process. To "give way" or, in other words, to surrender, is described by the 'surrendering self' very differently to "giving in" or "giving up". Unlike acceptance, surrender does not imply renouncing the object of desire. Instead, surrender requires the recognition and negotiation of the opponent, personified above as a Samurai warrior. Nearly without exception, the opponent that the 'surrendering self' pays attention to is an interoceptive quality. To "fight" this opponent is recognised as potentially self-destructive: "I realised if I tried to fight it, it would just set me up, I would die". Rather than accept the opponent, surrendering to the opponent implies actively "facing" and consequently "dissolving" the opponent: "if I surrendered to it, it would just completely vanish and let go and dissolve; the energy that I was feeding it was no longer there. It would just fall to pieces".

Surrendering, or giving way, is not equivalent to ignoring. It is a conscious interoceptive act of, firstly, confronting and recognising an internal quality of the self and secondly, "letting go": "let it go, let it pass by, don't resist it, don't battle with it, just give way". This act of "letting go" again differentiates surrender from acceptance as the act of renunciation does not require letting go. It is as if acceptance permits an ignoring of the opponent.

In comparison to acceptance, surrender is positioned differently in relation to either acceptance or fighting.

I27: I learnt to put my feet up, even just for five minutes at a time, lie down, put my feet up, take long baths and just lie and do nothing, really. Which was new for me. I developed the ability to lie down and do nothing and just look. It wasn't actually totally new for me. I used to do it when I was a child on the farm. I would just lie in the long grass and watch the clouds. Well that's not doing nothing, that's an amazingly important thing to do. Or I'd sit up a tree and just watch the birds, in their nests or talk to them or hang upside-down swinging from a branch you know, and just do nothing. Which isn't doing nothing at all.

Surrender is consciously narrated by the recovered participants as an action, it is something that the “mind does”. In relation to the modal structure of being-able with respect to doing, surrender is a being-able-to-do. Surrender, therefore, contradicts illness with respect to not-being-able-to-do. Surrender also represents being-able-not-to-do and, therefore, it is not opposed to acceptance as an expression of being-able-not-to-do. Surrender does not exist in contradiction to fighting and nor does it exist in implication with fighting as surrender implies being-able-not-to-do as much as it implies being-able-to-do. Surrendering achieves this by claiming not-doing as an action and as such it restores the capacity for action. The action of non-action is described by the ‘surrendering self’ as meditative.

10.4.1 Time and Emotion

For most of the recovered participants, the internal quality that stands as an opponent to which the ‘surrendering self’ consciously intends to give way was a feeling.

I21: I have in moments, my more healing moments, surrendered to whatever feeling, what is actually present at the time, whether that's been a thought, surrendering to what is, whether it's my mind's telling me that I'm bad, when in fact it's just my mind that's doing something or whether it is actually that I feel physically sick. I have surrendered to it at times and I guess that surrendering to me is actually just being present with what is. It's not like saying, ‘okay illness take me over’. It's just kind of like, ‘okay what are you? What is this? What am I experiencing at the moment?’

The chrononyms “moment” and “present” and the phrase “at times” are examples of the many references to time in the participants’ descriptions of surrender. The ‘surrendering self’ has the strongest temporal dimension of all the forms of self narrated by any of the participants. “Moment” and “the present” are chrononyms that the ‘surrendering self’ uses to designate a distinct period of time in which surrender occurs. These chrononyms are consistently characterised by immediacy. Surrender happens in the present moment and it relates to “what is actually present”. Bringing the “mind’s presence” to what is “present” in the “moment” is described as essential for surrender to take place each and every time. The presence of mind that is required is very specific. It is a form of self-investigation: “it's just kind of like, ‘Okay what are you? What is this? What am I experiencing at the moment?’”. Although the participants describe the gesture of surrender as requiring continuous performance, this does not take on the atemporal quality of acceptance.

The act of surrendering is itself “scary” and, consequently, it involves facing fear. Like the retrospective ‘having an illness self’, surrendering implies entering into the “unknown”. It involves “challenging the self” and “going beyond” the present “limits” of the self, even “being mad and neurotic”.

I28: Fear about surrendering to the illness ... surrendering to it, where was it going to leave me?

I23: Maybe one of my growth spheres is to lose my mind, to be thought of as being mad and neurotic, losing control of my emotions. Well, for a control freak that is going to be scary so face the truth, face the fear ... Don't resist it. There's a lot to be said for giving way.

Sometimes going beyond these limits involves “losing control” of “emotions” and almost without exception it requires “feeling”. Challenging the self by “feeling”, “losing control”, “going mad” or in some other way “going beyond” the present “limits” of the self are all expressions of fundamental transformations of self. Transformation of affective state through interoceptive action is a defining feature of the ‘surrendering self’. Although not exclusive, emotion is an important and nuanced focus within the interoceptive context to which the ‘surrendering self’ pays attention. The ‘surrendering self’ narrative often initially expresses emotional ambivalence about the act of surrender. The experience of surrender is accredited both positive and negative valence and the ‘surrendering self’ often narrates these simultaneously. The relative emotional sophistication of the ‘surrendering self’ narrative clearly contrasts this narrative with the ‘accepting self’ narrative.

10.4.2 Surrender and Judgement

Surrender also requires the cessation of judgement.

I21: I'd be thinking, ‘If I could just be more positive about this, I could get out of bed and I'd feel alright’ or, ‘If I just get up and do this and do this then I'll feel better’ or ‘If I just get on and actually do something’ and it was just hopeless physically, it would just make me worse. Then I'd be giving myself a hard time. It was like not actually acknowledging what was true for me, what was going on so I'd make myself do something and then I'd feel worse. I'd say, ‘Look you stupid idiot, you should not have done that because now you feel worse’ and so just a continual judging thing that would build up, which was really detrimental to feeling better ... I try to be gentle with it, I just try to be aware ... it loses its power. It might keep going but as long as I maintain the awareness of it, it will lose its power ... rather than damning the judge it's kind of just, ‘Oh yeah, you again’ and then it just loses its momentum.

Negative emotions are brought into existence in this passage *in absentia* through the reference to “positive” emotions. They are the internal quality that acts as the opponent in the participants’ quest to “do something”. The lexeme “just” signals the compulsion of this desire to “do”. Through the act of surrendering, the participant gives way to these negative emotions and lets go of the judgements that lead to the compulsion to act: “it was just hopeless physically, it would just make me worse”. In the process, the ‘surrendering self’ needs to “be gentle” and “be aware” of its own thought processes: the “continual judging thing”. When this thought process is recognised as self-destructive, the participant is able to let go of this habit and the habit ceases, it “loses momentum”. It is as if the ‘surrendering self’ acknowledges judgement as a form of craving or grasping and, consequently, is able to break the chain of causality at this point. The

extract above demonstrates the process of surrender in the face of the most common opponent, a negative emotion, and with respect to the most common habit, compulsive action. The ‘surrendering self’, like the accepting self, is making choices about the interoceptive actions it engages. It is also making conscious the interoceptive actions it chooses not to engage. In this way, the ‘surrendering self’ chooses being-able-not-to-do with respect to craving and grasping.

10.4.3 Becoming More Real

Several recovered participants made a specific connection between judging, feeling and the influence of “society” and “family”. In narrating their ‘surrendering self’, these participants commented that they felt “society” and their “family background” had discouraged them from feeling their emotions.

I21: There are a lot of ‘shoulds’ about how you should live your life and what you should do. There are certain things that come from family history, from generations ago that comes through. It's about certain things that you should do and how you should be in society that I guess I'd absorbed. They were just things like not showing emotions, you should get on with your life, you shouldn't explain how you feel.

The lexeme “should” and the phrase “certain things” refer to the presence of beliefs and judgements. “Absorbed” refers to the process of internalising these beliefs and judgements. One such belief is the belief that emotional expression is not sanctioned: “things like not showing emotions”. In contrast, achieving sanction, the participant believes, requires doing: “should get on with your life”. “Get on with” and “shouldn't explain” refer to the belief that emotions are not to be attended to. What this passage conveys, therefore, is that sanction is available at the cost of attending to emotions.

Several of the recovered participants commented that they had not learnt what an “emotion” “felt like” prior to illness and that it was through their “recovery” process that they “learnt” “how” to “feel” their emotions.

I23: I don't think I actually knew what a feeling was until I was around twenty six. I knew what ‘anger’ was and I knew what ‘happy’ was but I didn't have a great vocabulary on emotions so it was just like a drive thing. I've got to do something, got to accomplish something. Make something of my life. The drivenness ... now I know what a feeling is. I have more maturity, psychically, spiritually, physically. I'm a more real person. This has been a real blessing.

The ‘surrendering self’ expresses a growing awareness that, in the place of an “emotional” “vocabulary”, previously they had only a sense of compulsive action: a “drive thing. I've got to do something, got to accomplish something”. CFS becomes perceived as a “blessing” because the processes of illness and recovery bring the participants “in touch” with their emotions, allowing them to become “more real” persons. “More real” is opposed to compulsive action.

Becoming “more real” involves becoming more able to attend to emotion and being less defined by judgement and belief.

Considering these statements in relation to the modal structure of being-able-to-be, compulsion and judgement amount to forms of not-being-able-not-to-be and becoming more real requires a being-able-not-to-be. This being-able-not-to-be is precisely the position with respect to being-able that was observed to be absent from the ‘accepting self’ narrative.

10.4.4 Illness as a Teacher

The ‘surrendering self’ reassesses its relationship to the illness and commonly personifies the illness as a puzzle, a great teacher, a blessing, a gift, an opportunity and a journey.

I23: The important thing for me is to realise that this is a puzzle for me to solve and it's my journey and, ultimately, I'm the one that has to figure it out. And no matter how cruel that may seem, it's what I needed to go through, and I'm glad I can say that now, looking back. But even when I was going through it, that was my focus, that was my attitude.

I21: I see ME as being an opportunity, as a real gift because it's made me stop in my tracks and it's made me look at all these things and it's made me put my energies towards things that do ring true, have always rung true for me. Whereas, I think, if I hadn't had ME, I think I probably would have continued on living a life that wasn't so deeply satisfying.

This “teacher” gives “perspective”, “teaches” the ‘surrendering self’ not to “take anything for granted” and “draws” the participant “back in” to themselves. The illness becomes something that the ‘surrendering self’ can negotiate with and learn from. This aspect of the narrative, although pivotal, is quite exceptional in the context of the participants’ overall discourse on the illness experience. Nowhere else in their discourse on CFS do the participants so strongly intend to pay direct and sustained attention to the illness. This represents a degree of relationship between the participants and the illness that they otherwise narrate taking considerable steps to avoid. It stands in direct contrast, for instance, to the way in which the recovered participants retrospectively experience relating facing the unknown with respect to the ‘having an illness self’ as tantamount to reliving the illness (see section 9.6).

As part of the process of coming “back in” to the self, the ‘surrendering self’ describes choosing to see the illness as something that they own, “a puzzle for me”, and something that is their responsibility: “ultimately I'm the one”, “I needed to go through it”. With these statements, the participants communicate their need to own and instigate (do) their ability to respond to the illness, in other words, their active response-ability. The ‘surrendering self’ owns its actions. The gesture of coming “back in” to the self brings them to a stop: “made me stop”. Within this stop, the opportunity to reassess the direction of their “energies” becomes available. From this gesture of coming “back in”, the participants choose to focus on what “rings true”: “put my energies

towards things that do ring true, have always rung true for me". The participants describe this new focus as "deeply satisfying".

The participants establish what is "true" for them by engaging in a process of re-evaluation that "stopping" facilitates. The most common belief that the recovered participants re-evaluate is the importance they place on tolerating stress.

I2: The people that we really look up to are people who can take on lots of stress, you know, like taking lots of stress is a really good thing. The more you can take, the better person you are, that sort of thing. We think people are stronger because they can handle more stress and I don't actually think that's true anymore. I think the people who are stronger are the ones who just say no.

For the recovered participants, reassessing this belief goes hand-in-hand with actively choosing to reject this "way of being" and "coming" to a recognition of how "driven" and "busy" they have been.

I23: I've learned my pattern is to keep busy and active to cover up the feelings that are so intense underneath and so I'm learning, still to this day, to stop and face those feelings and let them filter through. I've learned techniques to let them pass through and move on.

"My pattern" here refers to a habitual belief, "cover up" refers to ignoring emotion. In contrast, "surrender" is the technique by which the participants "face those feelings and let them filter through". This passage consciously narrates the importance the 'surrendering self' places not only on accessing but also on attending or responding to "feelings".

In many cases, the new sense of response-ability the 'surrendering self' narrates was accompanied by a rejection of "quick fixes".

I2: I'm very suspicious of medical companies now. I won't take Panadol or anything like that. I'll tend to think, 'If I've got a headache, I'm better off to discover the cause of it than to actually just go pop a few pills'. I'm not looking for quick answers any more. When I first got ME it was like, 'Well, someone give me the pill for ME'. I don't want it any more. After a while you realise that it's not going to be like that. I think the same really of your whole health. That it's really your responsibility and I think we've just handed over so much responsibility to doctors and we just go along there.

This shift in response-ability was often articulated in tandem with a rejection of the perceived ethos of western medicine as a discipline that does not attend to the cause of health problems but instead offers "bandages" for symptoms.

10.4.5 Becoming More Integral

For the 'surrendering self', "facing drivenness" and "feeling emotions" also requires facing "meaninglessness".

I23: I think it would be like I've never been here. Meaninglessness is something very scary to face up too ... there is always something underneath the symptom. The symptom for me was drivenness. Driven to do activities, whatever activity is circumstantial. Behind that, if I

actually stopped, and that's why the disease was so wonderful, and it's a blessing because it made me look, if I actually stopped doing these things what would be left? ... I realised that, underneath it, I'd feel meaningless: that there's just nothing to life. There would be a void. Everything is meaningless.

Here, the opponent "drivenness" is referred to as "the symptom". The phrase "there's just nothing to life" and the lexemes "void" and "meaninglessness" refer to the state the 'surrendering self' "discovers" through the gesture of "letting go" in the face of this meaninglessness. Whilst facing emotions and "drivenness" allowed the 'surrendering self' to become more real, facing meaninglessness gives the self more "self" "integrity". This presents an interesting paradox. It is through being-able-not-to-be, described as the ultimate state of "nothingness", "void" or "meaninglessness", that the 'surrendering self' creates "integrity": a sense of "wholeness".

Having more self integrity allows the 'surrendering self' to "do things" in a way that feels more "true" or more integral.

I21: I was quite driven. I did a lot of things because I felt I should be doing things and I was always on the go. Whereas now, I guess, I'm much more reflective and more just doing things as I want to do them rather than doing things because I think I ought to be doing them. The fundamental change, I guess, is I've got different priorities of what's important to me to be doing now. Much more aware of what feels right for me at the time rather than just doing things for the sake of doing them ... before I tended to be focused on doing things, like doing tramps, doing cycling trips, doing kayaking trips, doing work, doing social things, whereas now, I guess, it is moving more towards being and it's more about reflecting on experiences I have and how they affect me: what is going on for me inside. Reflecting more on how what happens out there actually affects me and what rings true, what feels true about situations and what feels right for me rather than what feels what should be right. I think a lot of my life was run by external expectations or external indicators, feeders and stuff, whereas now, more and more, I'm getting more towards what's true for me and I guess that's what's more effective.

"Stopping" and "reflecting" allows the participants to reassess their "priorities" so that they can do what they "want" rather than what they "ought" or "should" be doing. As such, the 'surrendering self' is narrating a fundamental change in the motivation of action. "Moving towards being", in this sense of "being", does not imply not-doing. Rather, it is about doing whilst also "reflecting on" the "experience" of doing. It is doing and being. This suggests that doing what one "ought" to do does not allow for being-able-to-be. Equally, it does not allow for the self recreation process that being-able-not-to-be and being-able-to-do not-doing involve. For the 'surrendering self', "ought" and "should" are about doing according to the demands of the 'external' world: "run by external expectations or external indicators, feeders and stuff". In contrast, acting from their own 'inside' world involves the participants "being" "reflective", becoming "aware" of what is "more effective", "feels" "right" and "rings true". Fundamentally, acting from the "inside" involves paying attention to "how what happens out there actually

affects” the participants’ state, attending to “what is going on” “inside” and acting according to “what feels right for” them.

The ‘surrendering self’ describes doing what “rings true” or what is “more effective” as that which is “worthwhile” and “life giving” for both the self and others.

I27: I'd just been doing things because they had to be done, I didn't do things because I wanted to do them. Whereas when you haven't got the energy to afford to do much at all, you make sure that the things that you do are things that are life-giving to you, that encourage you, excite you, make you want to look through the next day rather than become mired in the mundane really. Those sort of shifts, shifts in relational terms as well, with my family and things like that ... your attitude is right, and you're living your life to make it worthwhile and that's all that anybody ever tries to live for in their life, isn't it? Is to make their life count for something, and if you make just one difference in the world, even if you're vastly incapacitated, and your one difference is to change somebody else's life for them, then it's been worth it, hasn't it? If you were on this planet for a purpose and you've done your job, you can retire happy. I was just kidding, [laugh] but you know what I'm saying. Yes, that's the light at the end of the tunnel. Some people, who are perfectly healthy all their lives, never actually come to realise that they were actually supposed to do something with their lives. When they get old and they think, ‘I never actually did anything worthwhile in my life and now I'm too old to’, and I know that's not true, because you're never too old to do something, but in one sense, it is a shame, that they didn't do something good while they had a chance, you know. And having something like CFS, makes you realise that, hey, you've only got one chance at this, and you better do what you can, you know, and make it worth it.

This passage narrates the change in attitude towards doing the ‘surrendering self’ represents. It involves the self in a global “shift” of perspective with respect to functioning in the world. The ‘surrendering self’ is consciously paying attention to interoceptive experience in relationship with the outer world.

10.4.6 Repositioning Mind and Body

A striking process of transformation narrated by the ‘surrendering self’ involves the conscious reassessment of the way the relationship between “mind” and “body” is perceived.

I10: When a task needed doing I just trained myself to ignore my body, just cut off from my body and force it to do what it didn't want to do ... forcing myself to listen to people when I didn't want to listen to them ... mind/body split: that was very bad for me, to do that.

“Ignoring” and “cutting off” from the body are narrated by the ‘surrendering self’ as the consequences of compulsive action, whether this is interoceptive action, such as listening, or exteroceptive doing: “do what it didn't want to do ... forcing myself to listen”. The ‘surrendering self’ consciously discovers that this “mind/body” split undermines health: “mind/body split: that was very bad for me, to do that”. Reassessing the relationship between mind and body provides the ‘surrendering self’ with a new sense of an intricate causal interconnection between mind and body. Consequently, the ‘surrendering self’ chooses to see health “holistically”, “as a complete thing”.

I28: I think one thing I've learnt is that problems in your physical state effect your mental and emotional states much more than I acknowledged before I experienced it myself ... I view health as a complete thing. I think, 'Healthy body, healthy mind' and the other way around ... I do think it's important to approach health holistically.

"Complete" and "holistic" above refer to an overall state of being, rather than to any specific discipline of holistic health.

The 'surrendering self' claims that reassessing the relationship between mind and body in illness "opened" its "eyes" to health. Health becomes the "number one concern". With this new relationship to health, the participants also acknowledge the need to more consciously "look after" themselves. Speaking on behalf of her body, one participant commented:

I21: "look after me, hey, hey, you know, I'm the one you are supposed to be looking after here, not everyone else in the world"

What the 'surrendering self' is choosing to "look after" or consciously consider is a global state of being.

Rather than consider the body "indestructible", "abuse" or "coerce" it, the 'surrendering self' narrates giving "permission to rest" and acknowledging the "fallibility" of the body. The 'surrendering self' learns how to "work with" the body and "respect it". The 'surrendering self' also acknowledges the body's ability to "heal" itself.

I27: I mean if you really think about it, it stands to reason that the human body heals most things, unless that thing is going to kill you.

The 'surrendering self' offers the body's ability to heal as a justification for rest.

The 'surrendering self' is characterised by processes of interoceptive transformation and change, in pragmatic, abstract and thymic dimensions. It is the most thymically varied form of self expressed by any of the participants. Although the abstract dimension predominates, action in the form of complex interoceptive doing is what this form of self is constructed around. Where the ill participants most positively evaluate the 'accepting self', the 'surrendering self' is the self narrative that is most positively evaluated by the recovered participants. In the interview process, it was often one of the first self narratives presented by the recovered participants.

10.5 The 'Recovered Self'

10.5.1 "Soul"

Those participants who had generally recovered at least six months before the interviews narrated a 'recovered self'. This contemporaneous 'recovered self' narrative is inclusive of the 'surrendering self' but develops a number of further dimensions. When these participants

described how they knew what “rang true” for them, they expressed a ‘recovered self’ that engaged in a process of “tuning in” to their “soul” or “spirit”.

I23: The most paramount thing, I reckon, to step towards health is the tuning in to the soul in whatever way that is. It will vary from person to person. Some can hear voices in their head, some can just have impulses or feelings about things or just know. So learning to tune that in, and you get that by, for me anyway, being still and quiet.

It is the “inner voice” of the “soul” that “speaks” their “truth” and “guides” them through the “maze” of the illness.

I23: Getting back to the soul, trusting that everything is perfect right now, that our soul will lead us through the maze. The head says, ‘I’ve got to understand everything, I’ve got to be in control’ therefore that conflict is still there and that’s why they get stuck and, I think, to some extent understanding is helpful and to some extent it’s not.

“Tuning in” and “getting back” refer to the act of turning interoceptive action back upon itself in self-examination, or observing the mind’s own inner workings. The participants use this gesture to allow themselves to “just know”, follow “impulse”, “feel” or listen to the “voices in their head” which allows the participants to “tune in” and “trust” that their “soul will lead”. Although these phrases appear somewhat nondescript, they are the way the ‘recovered self’ refers to a different way of “knowing the truth”, a way that contrasts with using the “head” to “understand” and be in “control”. Although “helpful”, using the “head” does not provide the participants with access to their “soul” and the “truth” they derive from it. Just knowing the truth of the soul does not detract from the experience of becoming more integral that is narrated by the ‘surrendering self’.

10.5.2 “Meditation”

Without exception, in describing how the ‘recovered self’ got “back in” to itself in order to get in contact with the “soul” or “feelings”, this self related some form of meditative practice. Sometimes “meditation” was as simple as watching the clouds.

I10: What was I doing? I was thinking about the universe, thinking about clouds moving and why they were moving and asking myself questions. I was questioning all the time, questioning, and noticing. Observing, very very observant.

“Questioning”, “noticing”, “observing” and “asking” “questions” of the self are all further examples of interoceptive action turned back upon itself in self-examination. The ‘recovered self’ described this meditative “time” as extremely important. This apparent doing nothing, contrary to the perceived opinion of others, was time in which the ‘recovered self’ was choosing to create the opportunity to “question” and “notice”. Some of the participants who narrated the ‘recovered self’ had learnt a specific meditative discipline. These included yoga, qigong and insight meditation.

I21: I got into meditation. I started going on retreats. The meditation I do is called insight meditation and it is basically learning about yourself, sitting and watching. Basically just sitting with the feeling that is in my body, where the sensations are and just allowing it to be there really, just watching it and allowing it, rather than distracting myself with something else to make it go away.

Whether a participant had learnt a specific meditative discipline or not, what is common to all the examples of the 'recovered self' narrated is the use of "questioning", "noticing", "observing" and some form of self-analysis.

The 'recovered self' also engages a process of "intense introspection", one in which the participant can "create" or "open up" the "space" to "grow".

I10: I reorganised my belief systems and I accessed, I didn't sit about doing this, it was a natural process that just went on, I accessed the belief systems my parents had. My parents' belief systems, that were different from each other, how closer I was to my father. One of his belief systems was, he would often say, 'Money is made to go round. It's about the heart that is giving. When we give to others we give to ourselves, all of that about sharing and generosity.'

This "intense introspection" became a space within which the participants were able to "reorganise" their "belief systems". It was a space within which the 'recovered self' became able to connect with "emotions" *within* the "body".

I21: I'm starting to understand more for myself the connection between an emotion like sadness, fear and anxiety and some feeling in my body. Whether it's a tightness around my chest, whether it's the sort of tight stomach or whatever. So it's just, for me, to stay with the emotion or to allow the emotion. The easiest way for me is to just, actually, directly experience what it physically feels like in my body. Whether it's tension or whatever, just to sit and just watch it ... if I actually just sit with it and explore what it is then it allows it to do what it has to do or move on. It often ends up with me experiencing sadness or experiencing tears or experiencing anger and that kind of sets it free, I guess.

In this way, the 'recovered self' takes the narrative of mind/body interconnection a step further than the 'surrendering self'. The 'recovered self' is not simply feeling and thinking on the one hand and acknowledging the body as relevant on the other. Within meditation, the emotions or "feelings" are "experienced" by the 'recovered self' "directly" through their bodily reality: "what it physically feels like in my body". As such, the 'recovered self' is consciously accessing and paying attention to proprioception. Connecting with this physical aspect of the emotions allows the 'recovered self' to "stay with" or "allow" emotions as opposed to "ignoring" or "cutting off" the body or the emotions.

Meditation, like surrender, involves "feeling", "noticing", "observing", "suspending judgement" and "analysing". What is distinctive to the narration of meditation by the 'recovered self' is the "spaciousness" that meditation promotes and the degree to which meditation involves deliberate "change", transformation.

I21: I'm describing my meditation. When I directly experience the feeling, it changes. You realise it's not a constant thing. If I'm ignoring it, I kind of feel like this pain in my chest won't go away but if I actually explore the pain, it will actually be a series of tingles or heat or whatever. So I'll just keep watching, just keep breathing into it and staying with it and it will change in my body and, with that, a change of thought will come into my mind, or feelings will come up. The whole thing will move and sometimes it disappears quickly, sometimes it moves somewhere else, but it's sort of changing, it's kind of recognising that, just that feeling of energy and what it's doing ... If it moves somewhere else, it might, just move up and down different parts of my body. Sometimes it will just move and I'll just have a great feeling of spaciousness. Sometimes it will just, move into tears in my eyes or something like that ... I guess that is why I do it, because it will change. I know it will change if I stay with it and usually it's freeing. It's like it's an unblocking of the energy, it's freeing. If I go into it with the intention that I want to free it, that won't necessarily do it, that's why I just have to sit with it.

It is the “freedom” the participants discover within the spaciousness of meditation that motivates them to do so. This meditative spaciousness is unique to the ‘recovered self’ narrative. One participant also described meditation as a means through which she could feel “positive” and “cleansed”.

10.5.3 Empathy, Sympathy, Compassion and Connection

As the ‘recovered self’ becomes more “aware” of emotion, a change in orientation takes place with respect to others. The ‘recovered self’ becomes more “empathetic” and “sympathetic”.

I27: I’m a bit more sympathetic than what I used to be. I care about other people’s feelings much more than I used to and I suppose, in one sense, it’s made me a better person.

The ‘recovered self’ describes becoming more “compassionate” and “connected” toward both others and the self.

I21: Basic qualities of existence: truth and love and compassion. From that place, the world can operate from a much healthier way of being, and, I guess, I can operate from a much healthier way of being and, I guess, I feel that the world can too. So it's trying to find that place within myself, which is always there, and trying to operate from that place. Operating from that place with my work, with my relationships, with my whatever ... It feels like a place of connectedness with myself and with others. It feels like a place of love, it feels like a place of compassion, understanding, all those sorts of words but connectedness is the main word ... Connected to myself, my mind, my body, my soul, connected to other people, connected to nature.

Here “place” refers to a state of compassion. Compassion is defined by the ‘recovered self’ as the state of being “connected”, “connected to myself, my mind, my body, my soul, connected to other people, connected to nature”. Ultimately, it is this state of connection that provides the ‘recovered self’ with a “healthy way of being”. Like the ‘surrendering self’, the ‘recovered self’ is paying attention to the interoceptive experience in relationship with the outer world.

The “recovered self” equally becomes “less tolerant” of “anyone” that is “emotionally manipulative”.

I10: My illness made me more compassionate, a lot more understanding of people. It's just like when I injured my back. I moved from thinking, 'What the hell's wrong with her? Why doesn't she just stand up straight?' to, 'My God! A back injury is the most awful thing' ... The illness made me hugely compassionate and I just believe people's reality now, where I might've been very cynical before, I just totally lost my cynicism. On the other hand, I'm less tolerant of people who are not compassionate. I'm very intolerant of people who try to emotionally manipulate other people. I can't stand it! I wasn't aware of that before.

The 'recovered self' defines "being emotionally manipulative" as being "disconnected" and this opposes connection as a "healthy way of being". Rather than the ability to do, the definition of health now involves connection.

The 'recovered self' is narrated by the participants in deliberate reflection on the overall experience of the illness and, particularly, the process of recovery. Like the 'self before illness', this contemporaneous 'recovered self' is coloured by the illness experience. It is not a neutral presentation of self. The participants' choice to speak about the "soul" or "spirit", "meditation", "empathy", "sympathy", "compassion" and "connection" needs to be viewed in this specific context. The 'recovered self' demonstrates the same interoceptive pragmatism as characterises the 'surrendering self' but is more thematically varied. With the inclusion of proprioception, the 'recovered self' presents the broadest range of interoceptive processes and arguably takes these processes to the greatest depth. The recovered participants look towards the future with the 'recovered self'. Consequently, it has a more varied temporal dimension than any other form of self narrated by the interviewees. The 'recovered self' is positively evaluated and expressed with both euphoria and dysphoria.

10.6 Analysis

10.6.1 The 'Accepting Self'

Semiotic analysis of the 'accepting self' suggests that this self accesses and pays attention to complex interoceptive action. From an enactive perspective, this suggests that the "accepting self" engages in L1 (see section 5.5), where L1 is the experience of not-being-able-to-do, and L2, the process of examining or becoming aware of the content of L1. In order to achieve L2, the 'accepting self' has suspended and redirected normal mentation as one of the two core processes of becoming aware. This gives the account of the 'accepting self' a certain phenomenal richness. It also suggests that the 'accepting self' shows interest (*chandra*) in and brings mindfulness or inspection (*smṛti*) to not-being-able-to-do.

Semiotic analysis of the 'accepting self' (section 10.3) reveals that this self narrative contains more emotional content than any other form of self narrated by the ill participants. This is a significant source for much of its phenomenal richness and suggests that the 'accepting self',

more so than any other form of self narrated by the ill participants, pays attention to the second aggregate, feelings and sensations. The ‘accepting self’ narrates re-evaluating how the self emotionally appraises not-being-able-to-do. Positively appraised not-being-able-to-do becomes being-able-not-to-do. It is noteworthy that, although the ‘accepting self’ begins to positively valence not-being-able-to-do, it does not follow that the previously associated behaviour has changed. This illustrates the importance of Colombetti’s (2005) point that it is not possible to conflate emotions and associated behaviours that are similarly valenced. It is this change in emotional state in relation to the same behavioural state that makes the ‘accepting self’ unique and potentially problematic to the participant’s desired progression towards recovery. The strong positive valence that is associated with being-able-not-to-do has no significant nuance. The ‘accepting self’ is principally about appraising action rather than emotion.

Semiotic analysis also suggests that the ‘accepting self’ shifts its criteria for self value from value derived from doing (human-doing) to value derived from being (human-being) (section 10.3.3). This demonstrates that the ‘accepting self’ does not question the assumption that the self can be given value in the first place. From an enactive perspective, this would suggest that the ‘accepting self’ continues to grasp after an ego-self in the sense that it continues to assert a continuity of self through a continuity of self value. This in turn suggests that the ‘accepting self’ fails to use intention to break the chain of causality between the links craving and grasping and so continues to enter into becoming in a state of ignorance. The ‘accepting self’ resolves the interest it shows in not-being-able-to-do through the renunciation of being-able-to-do. The ‘accepting self’ effectively resigns itself to being-able-not-to-do rather than relinquishing value in the self. Consequently, the ‘accepting self’ is unable to participate in the gesture of letting go with respect to the self. This would require being-able-not-to-be. Varela asserts that letting go is the second of the two necessary components to the core process of becoming aware (Scharmer 2000, p.5). If a self is not able to let go, then it will not be able to continually invent and reinvent itself, renew and recreate itself in the process of continually tackling the world (Scharmer 2000, p.10).

10.6.2 The ‘Surrendering Self’

The ‘surrendering self’, like the ‘accepting self’, engages in L1 and L2 in relation to the experience of not-being-able-to-do. Unlike any previous form of self narrated by the participants, the ‘surrendering self’ deliberately chooses to directly reflect on both the emotional and cognitive content of L1. This content, whether an emotion (section 10.4.3) or a judgement (section 10.4.2), is described as an opponent that the ‘surrendering self’ chooses to surrender to and “face”. By surrendering to and facing the opponent, the ‘surrendering self’ becomes “more

real” (section 10.4.3). The ‘surrendering self’ also narrates becoming more integral through facing “meaninglessness”, specifically being-able-not-to-be (section 10.4.5). From an enactive perspective, the gesture of surrender could be considered a description of “letting go” of the self that is accompanied by paying attention to emotion or feelings, sensations and dispositional formations or cognitive content. The act of surrender appears to require an acknowledgement and letting go of the appraisal of emotion and judgement. To surrender means not to judge, evaluate or appraise emotion and judgement but, rather, to give way to them. In so doing, the ‘surrendering self’ narrates a curiosity about emotion and judgement that is unique within the participants’ self narratives. The emotional content of this narrative is more nuanced both in character of emotion and valence than any other. For the ‘surrendering self’, knowing emotion is doing emotion and perceiving emotion ‘moves’ emotion.

Arguably, the ‘surrendering self’ succeeds in engaging the process of becoming aware. Through the continual recapitulation of surrender, the ‘surrendering self’ is able to invent and reinvent itself (Scharmer 2000, p.10). As such, the self that surrenders becomes more real by being less substantial, less determined. The gesture of surrender spontaneously invokes the virtuality of the self. This form of self is ontologically fragile. Varela comments:

Letting go is an interesting gesture, because in fact it’s almost like invoking the virtuality of the self, just putting it spontaneously on the table. Usually it’s life that makes you let go. You know what I mean, in the extreme cases of sickness or danger, or the disappointment of love, it just forces you into that gesture of letting it be, letting it go. (Scharmer 2000, pp.10-11)

Perhaps “letting it be” is precisely what the participants wish to convey by the “giving way” of the ‘surrendering self’.

By actively considering the cognitive-evaluative content of the relationship between mind and body, the ‘surrendering self’ continually recreates the location of the self within the psychophysical complex. The ‘surrendering self’ does not abdicate action in the pursuit of being, rather, this self narrative begins to demonstrate a new balance between the pragmatic, cognitive-evaluative and the emotional. It would appear that paying attention to all of these aspects of experience, particularly emotion, emotion appraisal and cognitive-appraisal simultaneously, allows the ‘surrendering self’ to more accurately sanction action, including non-action. That the gesture of surrender is narrated as so significant to the participants’ recovery from illness strongly suggests that emotion and emotional appraisal are indeed necessary components to successful evaluative processes such as sanctioning action. Perhaps it is the lack of attention to emotion found in the self narratives discussed in the previous chapter that leads to sanction processes that are not effective for the organism.

10.6.3 The ‘Recovered Self’

With ‘meditation’, the ‘recovered self’ takes surrender several steps further. Meditation, as it is narrated by the ‘recovered self’, like surrender, requires “noticing”, “observing” and “asking” “questions” of interoceptive doing. Meditation also enlists “analysis” and “intense introspection”. Arguably, from an enactive perspective, this suggests that meditation places an even greater emphasis on L2 than surrender. In the participants’ descriptions, meditation also involves an observed “opening up” of an interior “space” in which the participants find that they can “grow” and connect with their emotions within their bodies. For the ‘recovered self’, knowing and feeling emotions somatically is being emotional.

Could the choice to engage in meditation and opening up this internal “space” be a deliberate enactment of the gesture of letting go and an invocation of the virtuality of the self? By “directly” paying attention to the bodily reality of the “experience” of “feelings” within meditation, are the participants paying attention to the emotional-affective aspect of cognition?

Varela argues that emotion is fundamental to our ability to cope with the world; it contributes to our ability to act and to reason (Varela, Thompson, and Rosch 1991, p.78). I would suggest that meditation, for the participants, is a means of generating the kind of internal input that forms the basis of operational closure. Perhaps the ‘recovered self’ is choosing to invoke the mind’s ability to make changes to itself. This is a means by which the participants could change what Varela has described as ‘global states’ (section 4.15) and therefore influence the body’s ‘local states’. A sense of self is just such a global state. By paying attention to proprioception, the ‘recovered self’ is arguably also paying attention to local states as a means to change ‘global states’ such as judgements and beliefs.

Varela argues that the mind is fundamentally a matter of imagination and fantasy and that perception, such as proprioception or the bodily reality of the experience of feelings, is as imaginary as imagination is perception-based. This implies that in order to begin to pay attention to proprioception or the bodily reality of the “experience” of “feelings”, the participants must make changes in the global state of the self and, conversely, making a change in the self will change the way in which the world is perceived by the self. Perhaps what the ‘recovered self’ describes as the process of “tuning in” to the “soul” is a means by which the participants attend to a momentary global state of their being. It is possible that the “knowing the truth” that the ‘recovered self’ narrates is an example of *vipashyana*, the development of insight (see section 4.6).

Colombetti and Thompson argue that “given the intimate link between emotions and the body, emotions should be a privileged phenomena for attempts to reintegrate mind and body”

(forthcoming, p.2). The ‘surrendering self’ demonstrates precisely this point. Just as this self consciously narrates choosing to face the feelings and emotions that present as opponents, the ‘surrendering self’ also consciously reassesses the relationship between mind and body. The participants who express the ‘surrendering self’ present these two acts of reflection as often occurring simultaneously. The ‘recovered self’ implicitly accepts the integration of mind and body and utilises the ability to directly experience the somatic sensation of emotion in order to resolve emotion.

Varela argues that the mind is generated from affective-empathic phenomena, that is, the ability to interpret another’s mind. In other words, the act of cognising the self arises simultaneously with and is dependent on cognising the other. In the sense that empathy is therefore a measure of the virtual presence of the self, the empathy, sympathy and compassion that the ‘recovered self’ develops is a reflection of a self that is experiencing to a greater extent than previously observed. The phenomenal richness of the ‘surrendering self’ and the ‘recovered self’ similarly suggests that these forms of self are experiencing to a greater extent than, for instance, the ‘self before illness’ (section 9.2). Colombetti and Thompson comment that “feelings render consciousness personally relevant” (2005, p.7). Perhaps the naïveté of the ‘self before illness’ is symptomatic of the lack of personal relevance that this self attributes to emotions and the body. The ‘recovered self’, in contrast, deliberately accesses emotions and proprioception and, therefore, makes consciously available and personally relevant these aspects of experience. Emotions and proprioception are presumably available to the ‘surrendering self’ for processes of appraisal such as the sanctioning of action.

The emotional content of the ‘recovered self’ narrative is similarly nuanced to the ‘surrendering self’, both in character of emotion and valence. What both these self narratives reveal, however, is the challenge of finding a vocabulary with which to characterise the quality and dimensions of the valence of emotional/affective space.

10.6.4 Existential Feelings

Ratcliffe (2005) is concerned with the relationship between feeling, intention and the perception of being, or finding, the self in the world. He refers to feelings of being as ‘existential feelings’ and argues that these feelings are both bodily and a part of the structure of intentionality. As an aspect of intention, existential feelings shape thought, action and the experience of being in the world. Existential feelings are an expression of the relationship with the world the self is perceived to have. These “ways of finding oneself in a world are presupposed spaces of experiential possibility, which shape the various ways in which things can be experienced” (Ratcliffe 2005, p.45). Ratcliffe (2005) argues that existential feelings are more fundamental and

exist prior to more specifically directed feelings and emotions. In support of the existence of existential feelings Ratcliffe draws on the work of Damasio and Heidegger and evidence from psychopathology, particularly work on schizophrenia by Sass and Stanghellini and the phenomena known as the Capgras and Cotard delusions (Ratcliffe 2005, pp.51-56).

The unboundedness (see section 8.2) that the participants personify the illness as possessing, the heaviness of lacking energy (see section 8.4) and the “powerlessness”, “hopelessness”, “despair”, sense of being “out of control”, “in-valid” and “indefinable” that the participants describe as the “emotional impacts” of CFS (see section 8.10) are all remarkably close to the examples of existential feelings Ratcliffe offers (Ratcliffe 2005, p.45). Viewed as existential feelings, they represent a negatively evaluated departure from one’s previously assumed state of being in the world.

The grief or loss of the contemporaneous ‘having an illness self’ (see section 9.5) and the self absence that is common to both the contemporaneous and retrospective ‘having an illness self’ (see section 9.7) could also be conceptualised as existential feelings. These are clearly expressions of the participants’ state of existence or lack thereof. As Ratcliffe comments, “extreme grief may well be a relationship with the world as a whole, a sense of loss that structures all experience” (Ratcliffe 2005, p.46). As I have argued (see section 9.9.3), it is as if the grief and self absence of the ‘having an illness self’ are expressions of an existential relationship of lack with respect to the ability to do in the world. Perhaps the grief of the contemporaneous ‘having an illness self’ is a beginning to paying attention not to the specific aspects of feelings and sensations but rather the more global existential feelings Ratcliffe (2005) proposes.

Bodily feeling can be feelings towards the body or towards the world outside the body. According to Ratcliffe, existential feelings are bodily: “I suggest that existential feelings are feelings in the body, which are experienced as one’s relationship with the world as a whole” (Ratcliffe 2005, p.49). Ratcliffe likens existential feelings to Gallagher’s body image, rather than the prenoetic body schema.

The ‘existential feelings’ that I have listed are perhaps best understood at the level of the body image. They are ordinarily part of the background structure of experience, constituting ways of finding oneself in a world that shape more specific experiences. Nevertheless, they are phenomenologically available, as is evident from the various, usually metaphorical descriptions employed to communicate them. So they are part of the structure of experience, rather than an experientially inaccessible contributor to that structure. However, there may be a thin line between noetic and prenoetic as aspects of existential feeling. (Ratcliffe 2005, p.50)

In this research, the grief and self absence of the ‘having an illness self’ and the ‘being’ of the ‘accepting self’ may offer examples of existential feelings that are consciously felt as a

relationship with that which is outside the body: the experience of not doing and, therefore, not being in the world.

Similarly the ‘being present in the moment’ or ‘being aware’ that begins to emerge in the ‘accepting self’ and is developed in the ‘surrendering self’ are examples of the participants consciously identifying their relationship with the world. The “drivenness” that the surrendering self becomes aware of and the meaninglessness that this self faces are existential feeling states. The ‘being more real’, ‘becoming more integral’ and “wholeness” that are characteristic of the ‘surrendering self’ could all be expressions of existential feelings. When the ‘surrendering self’ is “being” “reflective” and becoming “aware” of what feels “right” and “rings true”, “more effective”, “worthwhile” and “life giving”, this self is consciously narrating existential feelings that express the process of attending to “what is going on” “inside” and shaping a functional relationship with the world on that basis. Being healthy is also defined by the ‘surrendering self’ through the existential feeling of completeness. These could all be considered further evidence for existential feelings.

The ‘recovered self’ is perhaps the self narrative most richly imbued with existential feelings. Ratcliffe (2005) identifies empathy, compassion and connection as examples of existential feelings. Arguably, the “trust”, “knowing” (the truth) and “tuning in” to the “soul” or “spirit” of the recovered self could also be considered existential feeling states. Most striking, however, is the “space” of meditation within which the ‘recovered self’ becomes able to connect with “emotions” *within* the “body” “directly” through their bodily reality. This could be an example of the self making noetic or phenomenologically available previously prenoetic proprioceptive aspects of existential feeling. Meditative space provides potential evidence for both the felt and the bodily aspects of existential feelings. It is interesting to consider to what extent this act of accessing the prenoetic contributes to the “freedom” and transformative potential of this meditative “spaciousness”. From the perspective of the current research, all of these observations raise the question of how existential feelings sit in relation to the aggregates.

10.6.5 Emotion and Goal Obstruction

Returning to the work of Lewis and Todd (2005), at a global level, the apparently increasing degree of attention paid to emotion within the self narratives presented in this and the previous chapter could support the claim that attention only turns to emotion when plans for action have been persistently obstructed. It is entirely possible that it is the persistent obstruction from the goal of efficacious action, actual and anticipated, that, for instance, prompts the ‘having an illness self’ to pay attention to the existential feelings of grief and self absence. Similarly, it may be the persistent obstruction from doing, in tandem with a desire to avoid the grief and self

absence of the ‘having an illness self’, that prompts the ill participants’ ‘accepting self’ to pay attention to the possibility of positively evaluating the position being-able-not-to-do.

In contrast, the recovered participants’ ‘surrendering self’ moves from the persistent obstruction from doing to a conscious assessment of emotions and judgements as opponents. If Lewis and Todd (2005) are correct and obstruction from action does result in attention to emotion, this could explain why the very conscious attention to emotion demonstrated by the ‘surrendering self’ contributes so significantly to recovery. Lewis and Todd ask: “what does emotional awareness buy us?” (Lewis and Todd 2005, p.231).

One possibility is that the extended integration of an explicit emotional consciousness catalyses awareness of intentions themselves. When we are pursuing goals, adjusting our actions to compensate for the obstructions in our way, we are not aware of the goals – only of the obstructions and our efforts to overcome them. However, explicit emotional awareness may compel us to include, in our appraisal of our actions in the world, an appraisal of what is propelling those actions. That would be the best way to make sense of the feelings we experience. (Lewis and Todd 2005, p.231)

It is perhaps no coincidence that the most common internal quality that stands as an opponent to which the ‘surrendering self’ consciously intends to give way is an emotion. It is the act of explicit emotional consciousness that allows the ‘surrendering self’ to become aware, for instance, of drivenness, the existential feeling of compulsive action. By paying attention to drivenness, the ‘surrendering self’ attends to the intention propelling action and, by doing so, opens up the possibility of reassessing this intention and the *modus operandi* that accompanies it. In other words, “with focal attention to one’s feelings and intentions dominating consciousness, there are now opportunities to engage volitional processes and aim them in a novel direction. ... [explicit consciousness of emotion] allows us to look up from the details of the world to the gist of our movement through it” (Lewis and Todd 2005, p.231).

10.7 Conclusion

The self narratives analysed in this chapter each present aspects of experience that have habitually been held in opposition. The ‘accepting self’ acknowledges the opposition of doing with being, leaving this opposition unquestioned. The ‘surrendering self’ reassesses the oppositions between mind and body, thinking and feeling. The ‘surrendering self’ and ‘recovered self’ narratives demonstrate the ability to ‘look up’ from the detail of these oppositions, to perceive and conceive of a novel direction in which to take the self. What this new direction entails is an acknowledgement of the dynamic interconnection within experience of mind, body, emotion and world. This requires more than changing thought perception of experience; it involves the per-cept-ion of the relationships of dependency and mutual constraint between each

of these aspects of experience. The participants appear to achieve an understanding of the embodied virtuality and ontological fragility of self experience. The tools the participants enlist to observe and invoke change within the self relationship to mind, body, emotion and world are the action states of surrender and meditation.

11. “Energy”

11.1 Introduction

Within the participants’ discourse on CFS, the most commonly and most substantially related narrative is about the participants’ experiences of their “energy”. Centering around the use of the lexeme “energy”, this narrative is also one of the most complex aspects of the participants’ discourse. Despite the participants reporting considerable difficulty in finding expression for the content of what they wish to convey about “energy”, this narrative is related remarkably consistently across both the ill and recovered participants. The “energy” narrative hinges on a dichotomy of “having” or “lacking” “energy”. The participants’ narrative of “having” “energy”, section 11.3, and “lacking” “energy”, section 11.4, both present ways in which “energy” moves and changes. “Having” “energy” is correlated with experiences of “spontaneity” and “clarity” (see section 11.3.1) The somatic, emotional and mental experiences the participants correlate with “lacking” “energy” are discussed in section 11.5. What “energy” is, according to the participants, is discussed in section 11.2. How the participants attempt to “manage” their energy is presented in section 11.6. Finally, what the participants convey about “energy” in relation to recovery is discussed in section 11.7.

The semiotic analysis of the participants’ narrative presented in the sections mentioned above is based on the participants’ expressions of the phenomenological invariants that contribute to the “Energy” cluster (Figure 5). An enactive analysis of this material is presented in section 11.8. Potential neurological and physiological explanations for the participants’ experiences of “energy” are outlined in section 11.8.1 and the chapter is concluded in section 11.9.

Numerous authors within anthropology, sociology, psychology, psychoanalysis, health and philosophy are exploring diverse understandings of the concept of human energy (Blachowicz 1975; Cheng 2002; Cheng 2002; Frank 2000; Gould 1991; Marks 1977; Ryan and Frederick 1997; Shope 1971; Watson 2003; Winter 1971; Yasuo 1993; Gallo 2005). This literature is not reviewed here because the enactive analysis of the participants’ “energy” narrative suggests that what the participants are describing as “energy” is actually an experience of contact (see section 4.11).

11.2 What “Energy” “Is”

In their descriptions of the lexeme “energy”, the participants present directly their understanding of what energy “is”. In semiotic terms, they convey a highly abstract concept. Energy is never presented as having any immediate concrete physical reality and it is always described in

relationship to another aspect of the participants’ experience. Despite this highly abstract quality, energy is not restricted to the participants’ inner mental world. “Energy” is conveyed as connected to the participants’ experience of interoceptivity, exteroceptivity, and proprioception, mind, body and world. Any analysis of this most central aspect of the participants’ experience of CFS that is concerned to engage this narrative on its own terms cannot, therefore, employ a mind/body dualism or a separation of the inner and outer worlds of experience.

The participants describe energy as being “ubiquitous”, “everywhere” and “in every living thing”. Energy is literally universal: “it is the universe” and “everything in the universe has energy”. Energy is what creates the possibility for life:

I10: Energy is what keeps me alive. If there is no energy then one gives up, I suppose.

In this context, to “give up” for the participants implies to cease living. Most of the participants perceive themselves as individual in relation to the ‘universality’ of what “energy is”.

Energy is both subject and object. Through the lens of the actantial narrative schema, energy is both actant¹⁰⁷ and helper¹⁰⁸. Not only is energy “ubiquitous” to the participants’ inner and outer lives and universally able to create life, as an actant, energy possesses the anthropomorphic qualities of being able to communicate and “having” “intelligence”: “whether we choose to listen or not, energy can communicate”. Within the participants’ energy narrative, the isotopy of a ‘field’ underpins the semantic field¹⁰⁹ that conveys ‘what energy is’. Energy is an omnipresent ‘field’ of life giving intelligence. Almost all of the participants convey some sense of living within this ‘energy field’.

11.2.1 “Energy” in Direct Experience

Given the degree to which the participants describe this ‘energy field’ as “ubiquitous”, it is surprising how few report any immediate experience of actively interacting with this ‘field’. A small number of participants describe the experience of perceiving the energy of other people.

I28: I know when I am in the presence of healthy energy and when I am in the presence of unhealthy energy. ... I suspect that during those years I became a lot more alert to that in people.

¹⁰⁷ “An **actant** can be thought of as that which accomplishes or undergoes an act, independently of all other determinations. Thus, to quote L. Tesnière, from whom this term is borrowed, “actants are beings or things that participate in processes in any form whatsoever, be it only a walk-on part and in the most passive way”. From this point of view, “actant” designates a type of syntactic unit, properly formal in character, which precedes any semantic and/or ideological investment” (Greimas and Courtés 1979, p.5).

¹⁰⁸ “**Helper** designates the positive auxilient when this role is assumed by an actor other than the subject of doing: it corresponds to an individualized being-able-to-do which, help to bear on the carrying out of the subject’s narrative program. It is paradigmatically opposed to the opponent (which is the negative auxilient)” (Greimas and Courtés 1979, p.141).

¹⁰⁹ “A semantic field comprises all the meanings (semes) attached to a particular signifier in the text. The signifier ‘fame’ may thus include the meaning ‘celebrity’, ‘stardom’, ‘repute’, ‘honour’, ‘glory’ or ‘eminence’, ‘illustriousness’; the semantic field of ‘joke’ might comprise ‘witticism’ and ‘anecdote’ or ‘prank’, ‘trick’ etc. The term semantic field is often interchangeable with that of lexical field” (Martin 1994, p.114).

The use of the lexemes “presence” and “alert” suggest that another’s energy is something that the participants are able to perceive. These participants describe choosing to spend time with “people” whom they find “energising” or “recharging” to interact with and choosing not to spend time interacting with those they find “draining”. In their interactions, these participants are affected by the energy of others. They do not convey any sense of energetic exchange, however. Others’ energy has ‘quality’: “healthy” energy is energy that the participants find “energising” or “recharging” whereas “unhealthy” energy is “draining”.

One participant related literally receiving energy from another.

I5: I had an amazing experience one time. I had a friend [visit]. They sat at the end of my bed and they had a hold of my feet and while he had a hold of my feet I could talk. When he took his hands away, I had no energy. It's like I can get energy from people and when they go, they take their energy that I was using with them. I use other peoples’ energy, somehow I draw on it. I don't know whether they feel drained at the end of it, but that is what I can do, and different people, you know you're going to get more energy from than others, or a different sort of energy. That was really weird, that day though. [I] could literally feel energy flow. Talking was easy but when he took his hands away I was just sort of saying the odd word, odd phrase.

“Different people” provide “more” energy than others and “a different sort of energy”. Here again energy is conveyed as having ‘quality’ and being present in different ‘quantities’. In these examples, the ‘qualities’ of energy are experienced as the different affects interacting with others have on the participant’s own energy. Phrases such as “get energy from people”, “use other people’s”, “draw on it” and “literally feel energy flow” suggest that this participant not only experiences the affect of another’s energy but also experiences a connection with the other person’s energy and, through this connection, the experience of an exchange of energy. The participant presents this experience of exchange from a passive position. The phrase “I don't know whether they feel drained” suggests that the participant is not able to assess the impact of their connection on the other person. Despite the experience of energy exchange, the state of the others’ energy and the others’ experience of connection remains inaccessible. From this arises the sense that the ‘other’ and the ‘self’ are discrete with respect to energy. Such discrete comments point towards an apparent absence in the participants’ ‘energy field’ concept.

Only one participant describes the direct experience of energy as a “field” that “flows” through and within them: one that contains “blockages”.

I21: When I was doing [qigong], I started to feel energy through my body, and sort of became aware of an energy field and energy blockages.

Here the “field” of energy is felt through the body. Unlike the earlier examples, however, it is not given parameters that are limited to the body. This participant alone describes a more reciprocal concept of her permeability to the ‘energy field’. A relationship of reciprocal

permeability is extremely rare within the energy narrative. This rare occurrence brings the absence of reciprocity to attention.

Whether it is living within the ‘energy field’, being “alert” to the “presence” of healthy or unhealthy energy, “using”, “drawing” or “getting” energy from another, “feeling energy flow”, or “feeling energy through my body”, it is clear that the ‘energy field’ conveyed by the participants is perceived.

11.3 “Having” “Energy”

Within the energy narrative, the participants not only describe energy as a ‘field’, they also convey energy ‘states’. This ‘state’ isotopy is principally conveyed through the participants’ references to “having” and “lacking” energy.

Having energy refers to the ‘energy state’ of being able to “act”, to “do anything and everything”, of being able to “get off your seat to do it”. Having energy is:

I28: The ability to act, the quality of being able to perform a task, to be motivated and able to perform an action.

Within the actantial narrative schema, the ‘having energy state’ can be described as a helper. For the participants, the ‘having energy state’ creates the possibility for interoceptive and exteroceptive action, motion and transformation. The ‘having energy state’ is, therefore, a key component to competence. It allows the participants to move from a virtual state of existence to an actual state of existence with respect to being-able-to-do. In other words, the ‘having energy state’ is the participants’ definition of what it means to be competent, to be able to be a subject of doing. In this sense, *being* a subject of *doing* requires a state of being: the ‘having energy state’. The ‘having energy state’ is the ‘state’ from which one can do; state and subjectivity, patience and agency intersect. The ‘having energy state’ is a positively evaluated ‘e-motion-al state’.

11.3.1 “Spontaneity” and “Clarity”

Almost all of the participants describe two correlates of the ‘having energy state’. The first is a sense that there is “spontaneity” in their lives. The examples the participants give of “spontaneity” are, without exception, very simple. The ability to make a meal, for instance, without having to “go through the whole process of considering whether it’s worth the physical effort of lifting my body up, walking across, checking it, making a decision about it and then going” back “to the couch”.

I5: If it’s spontaneous and I can just keep going, then I’ve got energy, whether it’s physical or mental.

“Spontaneity” in these instances refers to a general sense of “ease”, “effortlessness” and reliability with respect to being-able-to-do simple life activities. Throughout the participants’ descriptions of lacking energy and the ‘having energy state’, the lexeme “just” is used to indicate the presence or absence of “ease” or ability with respect to being-able-to-do.

The second correlate of the ‘having energy state’ described by the majority of the participants is a sense of “clarity” in their thoughts and actions and, particularly, “clarity” of their senses.

I19: When ... I had heaps of energy everything was really clear to look at, everything was brighter. Usually everything is slightly numb-feeling on me. Touching something isn’t as clear.

Several of the recovered participants described “suddenly” “realising” “one day” that they were able to perceive “things” that they had not realised they had become unable to perceive during illness. The suddenness of this realisation strongly suggests that this is an instance of the participants witnessing a change in their own state of being. For the participants, this renewed clarity comes to indicate that they are “recovering”. Recovering from CFS here implies recovering being-able to sense and perceive.

In the realisation of the interoceptive actions “sensing” and “perceiving”, the ‘having energy state’ acts as a helper. Similarly, the ‘having energy state’, expressed through the quality of spontaneity, helps the participants realise exteroceptive action. In both cases, the ‘having energy state’ is a key requirement for the establishment of competence. As correlates of the emotional ‘having energy state’, both spontaneity and clarity are evaluated positively.

11.3.2 The ‘Having Energy State’ and Movement

A striking characteristic of the participants’ descriptions of energy is their reference to movement. When the participants have energy, their energy “flows” and “moves” through them “easily”. Energy is in motion within the ‘having energy state’. Energy “just comes” and this “feels wonderful”. The participants comment that when energy is “flowing” or “moving” they do not “need to think” about whether they are “using energy up”. Rather, they feel “confident” and able to “rely” on their energy, their “body” and their “brain”.

I21: Free flowing energy is like being in harmony, things being connected, being able, energy being available and I’m able to do things without thinking about my energy.

For the majority of the participants, being aware of the “presence” of energy, the ‘having energy state’, ensures the competence to act but action is realised when energy “moves” or “flows”. It is only when energy is in motion within the ‘having energy state’ that performance and transformation actually occur for the subject of doing. For a small number of the participants

having energy and energy “moving” are synonymous. It is when the ‘state’ of their energy changes that these participants become aware of energy.

Energy “flowing” and “moving” provides a small number of the participants with a sense of “connection” to “the universe”. Despite this sense of “connection” and the sense of energy “flow”, these participants do not describe any location from which this energy is sourced or generated, internal or external. The participants do not, for instance, assume that the energy they have has come from the “universe” to which they are “connected”.

An absence of explanation for the source of the energy the participants have is present in all the participants’ descriptions of the ‘having energy state’. This apparent absence suggests that the absence of reciprocal permeability in the participants’ energy ‘field’ isotopy is also present in the participants’ having energy ‘state’ isotopy. Abundance and transformation are isotopes that underpin the participants’ ‘having energy state’ narrative. An abundance of energy and an abundance of movement within energy, for the participants, provide the experience of an abundance of both interoceptive and exteroceptive transformation.

11.3.3 “Energy” and “Health”

When the ill participants imagined what it would be like to have recovered from CFS, they described “wellness” or “health” as “being” “full of energy”. In their retrospective descriptions of their energy prior to illness, both the recovered and ill participants describe their energy as “unlimited”.

I7: I’ve been the six hundred miles an hour woman since the day I was born. I’ve had unlimited energy, you know, but I didn’t notice. I just thought everyone else was slow. I never saw myself in that context. I never had a grip on that. I would work a fulltime job and go out every night and have a dinner party and come home and cook all this stuff and have ten other projects of my own on the go. Someone [would] come round at eleven o’clock at night and I’d do something on the computer, and I just never thought about it. Go, go, go, [claps hands] go to sleep and then I was up again, eight hundred miles an hour the next day. Never knew myself any different.

Prior to illness, both the ill and recovered participants describe themselves as being “very energetic”, “extremely energetic”, as “always having energy in abundance”, “always being active” and “always having a lot of energy”. This retrospective account is undoubtedly constructed in relation to the illness experience (section 9.2). Nonetheless, in this relation, it is clear that for the participants the ‘having energy state’ connotes “health”. The use of “always” suggests that energy was omnipresent, or at least reliably accessible.

11.4 “Lacking” “Energy”

In contrast to the ‘having energy state’ of “health”, both the ill and recovered participants describe “illness” as experiencing a “lack” of energy. In the ‘lacking energy state’, the participants’ experience energy as “lacking”, “depleted” “low”, “flat”, “slow” and “way down”. Common phrases the participants used to describe the ‘lacking energy state’ included: energy is “not there anymore”, “just not there”, “no energy to do anything other than survive”, “not an ounce of energy”, “none whatsoever”, “no physical energy”, “no longer available”, “there is nothing there to flow”. Here “no” and “none” function as absolutes that reinforce the extent to which energy is lacking. Lack or absence is one of the isotopes that underpins the ‘lacking energy state’. The participants “just” “haven’t got it”, “haven’t got energy now”, “don’t have any energy”, “don’t have any of it”. “Don’t” and “haven’t” signal the absolute extent to which the participants experience energy as lacking. The participants most often refer to this ‘lacking energy state’ with the lexemes “tired” and “exhausted” and consistently evaluate this state negatively.

11.4.1 The ‘Lacking Energy State’ and Movement

The participants’ use of movement in their descriptions of the ‘lacking energy state’ is similarly significant to the place of movement within their descriptions of the ‘having energy state’. Energy is described as: “draining away”, “draining out”, “coming out”, “draining out of my big toe”, “trickling away”, “leaving”, “ebbs out of you”, “going down”, “dragging”, “leeching out”, and “running out” as if “corks fell out of my feet”. Common to all such references is a sense that energy is unexpectedly and uncontrollably moving out of the participants’ bodies downward. One participant, who described this draining feeling through the metaphor of filling up with smoke, was the only exception.

I7: [It] just felt like a sweep of energy. In a metaphorical sense, how I would describe it is my body was filling up with smoke. That's what it felt like ... just completely filling with black smoke. That's the image I have for it. But it felt like a wave that I couldn't stop and it wasn't like, whoosh, standing in the sea, it was more gradual but something you couldn't argue with ... If I had to say, which way [the smoke moved] I'd say up, but I'm not entirely sure. ... Whole body ... everywhere really. I mean not literally black smoke but that's the best language I have for describing what that feeling was like. ... very heavy.

In this description, the energy leaving is still uncontrollable and unexpected, however, it rises rather than descends and remains contained within the body.

Occasionally, the participants portray this ‘lacking energy state’ as if it is initiated by an external agent: “someone pulled the plug out”, “someone switched the power off”, “taken out”, “pulled the corks out of my feet, the corks out of my emotional source”.

I21: You had energy flowing into your body; it was supposed to fill you up. Someone just pulled out the plug at the bottom so it just never quite got into you. It just kind of went in and out again. It never kind of went through your system ... it was just frustrating.

This external agent is never given an identity.

Despite these often vivid descriptions of energy “draining” or “leaving”, the participants do not describe where this energy goes when it “leaves”. Likewise, the participants do not describe any internal or external location from which this energy has originated.

Both the ill and recovered participants describe the “draining” “loss” of energy as if it “dumps” them “down”, “flattens” them, leaves them feeling “washed out”, “totally drained”, “absolutely gone” and “wiped out”. In contrast to the “flowing” energy of the ‘having energy state’ that facilitates transformation and the realisation of action, the “draining away” of energy leaves the participants “depleted” of energy. The ‘lacking energy state’ is one in which energy becomes unavailable. Consequently the participants cannot fulfil the requirements for competence with respect to either interoceptive and exteroceptive action. For the participants, this corresponds with the inability to actualise virtual subjectivity. In other words, the ‘lacking energy state’ amounts to a description of not-being-able-to-be a subject of doing. Corresponding with “lack” or absence, the isotopy of stasis also underpins the participants’ descriptions of this negatively evaluated ‘e-motion-al state’.

11.4.2 “Blocked” “Stuck” “Energy”

Although the majority of the participants describe energy being unavailable in terms of the “draining away” or “running out” of energy, a small number of the participants describe their energy as “lacking” and “unavailable” to them when it “gets stuck”, “blocked” or “won’t flow”. In this respect, “draining”, “blocked” and “stuck” energy are synonymous: they represent an absence of available energy and a consequent inability to do. This brings into question any assumption that the metaphor of energy “draining” necessarily implies that energy is, in fact, moving. Likewise, it suggests caution with respect to the assumption that “flowing” energy is, in fact, moving. What is striking in the descriptions of “blocked” or “stuck” energy is the degree to which they convey the isotopes of stasis. When energy is “stuck” or “blocked”, the participants represent both themselves and energy as unable to move. Stasis becomes paralysis. For the participants, a lack of energy connotes a stasis or lack of movement of energy which corresponds with a lack of ability to transform. This stasis of energy is also an absence of energy and subjectivity.

The participants attempt to identify “why” their energy initially becomes “stuck” or “blocked”. Although they do not succeed in doing so, they do assert that their “emotions” do not

seem to cause their energy to “stop” “flowing”. Several of the participants nonetheless observe that activities that they find “interesting” and “stimulating” seem to encourage their energy to “flow”. These positive “emotions” act as helpers for the subject energy. In these statements, the participants do not convey any sense that the “blockage” has changed. “Blocked” or “stuck” energy remains synonymous with lacking energy. The participants do not identify any source from which the energy comes when it “flows” as a result of “stimulating” activities.

Whether energy is lacking because it is “draining away”, “blocked” or “stuck”, the majority of the participants claim that energy is completely “unavailable” to them. There is one exception.

I21: When I feel sick now it's like someone's pulled the plug on my energy. That's the feeling, like someone has just pulled the plug and all the energy has run out. But I guess I'm starting to feel that more as like an energy blockage. It's kind of like the potential energy is still there but, for some reason, it's just blocked, and it's not flowing through me so the different energy levels are to do with where my blockages are at the time, or about whether its free-flowing energy or not.

Unique to this description is the participant’s assertion that “the potential energy is still there”. Although static, “blocked”, energy is not absent; it is present and potentially available.

Whether the participants are referring to energy within the ‘having energy state’ or the ‘lacking energy state’ and whether this energy is “stuck” or “flowing”, without exception the participants consistently relate the state of motion of energy. Motion and transformation are key isotopes founding the participants’ energy state narratives.

11.4.3 “Unpredictable” “Energy”

Without exception, the participants claim that the changes in their energy are not only “uncontrollable”, they are also very “unpredictable”. The participants do not provide descriptions of how their ‘energy state’ changes from the ‘lacking energy state’ to the ‘having energy state’. Regardless of the ‘state’ change they are describing, the participants unanimously claim that they cannot identify any one distinct cause for the changes in their energy.

I5: I never knew whether I could go [to town] or whether I couldn't go. I wouldn't know what I was going to be like from [now to] an hour later. Then out of the blue I'd get this energy.

From the participants’ perspective, these “unpredictable” changes in the state of their energy do not seem to correspond to their activities. In some cases, for instance, the participants described being-able to sustain significant effort. In other instances, however, the participants describe their energy “draining away” during very simple tasks.

I5: I was filling up a hottie, and it was like my energy just voomph. It was absolutely gone.

The unpredictability of their energy compounds the participants’ sense of helplessness. In this context, “helplessness” connotes not-being-able-to-do.

I5: Every day is different, in some way. You feel helpless, and that's scary, and the more helpless I felt, going back a bit, the harder it actually was to ask anyone to help me, because I couldn't repay them.

Being “helpless” refers principally to the participants’ inability to “help” or do for themselves. The unpredictability of the participants’ energy, however, also impacted on their perceived ability to respond to others, to “repay” others for their assistance. Feeling unable to “repay” others and choosing, therefore, not to engage others’ help increased the participants’ sense of isolation.

Several participants expressed that the lack of predictability with respect to energy substantially contributed to their loss of “confidence” and sense of “trust” in themselves.

I26: Loss of trust in myself, not being able to trust myself from day to day to be able to, not being able to say, ‘Tomorrow I'll do this’. Or, if someone says, ‘Let's go and do this on Sunday’, and, not being able to say, ‘Yeah, I'd love to’ and know that I'd be able, up to it. So, that unpredictability, unreliability, loss of energy.

Central to this loss of “trust” and “confidence” in the ‘self’ is the “loss” of being-able-to-do predictably. Predictable energy is important for the possibility for action and transformation that it guarantees.

The participants describe the “unpredictable” changes in energy as “sudden” and often involving a sense of “collapse”.

I13: It's usually in that state when it's bang, it hits me and I've got to go to bed now. That's it, I just have to drop everything. It's just fatigue, it's just incredibly, incredibly, tired ... I've just got to go to bed, and I crash. And I crash, quickly and deeply. I mean my neighbours have been burgled and I haven't even heard them, smashing up glass, when I'm in that state and that can happen once a month to once every six months.

Other phrases the participants use to describe this energy transition include: a “sudden drain” or “sudden change” where energy is “very quickly lost”. It’s as if “bang”, or “crash”, they have “hit the wall”. Their descriptions of these “sudden” changes in their energy are very similar to the participants’ descriptions of “relapse” (section 8.3).

Sudden, unpredictable changes in the state of the subject of experience are usually associated with the thymic dimension: the impassioned changes in the subject’s state of being that occur with strong emotions. This analysis argues that the participants convey e-motion-al states through their energy narrative. Although the participants specifically state that they cannot identify the specific activities that cause unpredictable changes in their energy, from their perspective, these sudden changes in their energy are most closely associated with being-able-to-

do or not-being-able-to-do. This provides another example of the way in which, in order to communicate their experience, the participants’ energy narrative traverses both the thymic and pragmatic dimensions of discourse.

There is a striking similarity between the unpredictability of the illness (see section 8.2) and this unpredictable “energy”. Could this suggest a more fundamental correspondance?

11.5 The ‘Correlates’ of the ‘Lacking Energy State’

The ‘having energy state’ provides the participants with access to the positive qualities of spontaneity and clarity. According to the participants, the ‘lacking energy state’ correlates with specific negatively evaluated “physical”, “emotional” and “mental” experiences. The participants assert a causal relationship between the ‘lacking energy state’ and these ‘correlates’, claiming that the ‘lacking energy state’ produces these correlates. Common to all these ‘correlates’ is the participants’ assertion that each correlate relates to the experience of not-being-able-to-do. The participants rarely refer to these ‘correlates’ as “symptoms”, rather, they are conveyed as the specific consequences of being in the ‘lacking energy state’. Almost all of the participants claim that the relationship between the “presence” and “severity” of these ‘correlates’ and the level of their energy is “proportional”: when the participants energy is “low”, “lacking”, “stuck” or “blocked”, the ‘correlates’ of the ‘lacking energy state’ are proportionally present. On the other hand, at times when the participants’ lack of energy is relatively mild, the ‘correlates’ of the ‘lacking energy state’ are described as minimal or completely absent. The participants also express that some of the ‘correlates’ of the ‘lacking energy state’ further limit the energy that is available to them, whilst other ‘correlates’ do not.

11.5.1 The Somatics of “Lacking” “Energy”

The majority of the participants consistently claim that specific experiences which they identify as “physical” are the result of being in the ‘lacking energy state’. Where “spontaneity” and “clarity” are ‘correlates’ with the presence of energy, these “physical” ‘correlates’ are some of the most tangible ways in which the absence of energy takes form. The participants often refer to these ‘correlates’ as a lack of “physical energy”. In the participants’ experience, “physical energy” does not refer to energy that is physical, rather it refers to the ways in which energy functions as the motive force for the pragmatic. When “physical energy” is absent, physically experienced correlates arise.

11.5.1.1 “Agoraphobia”, “Panic” and “Anxiety”

Several participants claim that one of the “physical” ‘correlates’ of the ‘lacking energy state’ is a “physical” experience they call “agoraphobia”. Most commonly, this “agoraphobia” occurs when the participants are in “supermarkets”, on “farms”, “walking home” from public transport or, in extreme cases, whilst “walking” to the “mailbox”. It is noteworthy that, although all of these locations are outside the home, not all of them involve large open spaces.

I5: I was walking across the park and I could feel my energy draining but I thought, ‘Oh no, I’ll get there, but I won’t be doing this again in a hurry’. My energy just seemed to just drain away and then, I didn’t know whether I was going to fall down, or fall in a hole. I think my heart was beating, not really pounding or anything. I suppose there was a bit of panic, not wild panic, and I felt like I was just crashing, crashing down, everything was crashing. I think I spent the next two months in bed. Not from the agoraphobia, but everything else just went as well.

In these passages, the sensation of “crashing” or “falling” “down” is more specific to the participants’ descriptions of “agoraphobia” whereas the experience of energy “draining” “away” and their “heart” “beating” or “pounding” is also present in the participants’ descriptions of “panic” and “anxiety”. Common to all of the participants’ descriptions of these ‘agoraphobic experiences’ is the assertion that the “agoraphobia” occurs when they do not have enough energy to “cope” with the task at hand, even when this is one of the “smallest” tasks required to “survive”. These ‘agoraphobic experiences’ only occur when the participants experience their energy as particularly “low”.

One participant described her “panic attacks” and several participants described their “anxiety” as similarly consequential to the “world” being “just too much” for them, given their “energy resources”. Like “agoraphobia”, the participants claim that these experiences of “panic” and “anxiety” often take them by surprise and do not occur when their energy is adequate to the task at hand. “Panic” and “anxiety”, like “agoraphobia”, are ‘correlates’ of the ‘lacking energy state’.

When coping in the “world” requires more energy than is available, one participant describes her resultant “anxiety” as “becoming ungrounded”: being “out of my body, totally out of touch with myself” and “out here”, “out there, out of yourself”, and “not in touch with the universe”. When this participant is “ungrounded”, their “thoughts” are “scattered”. The experience of “scattered” “thoughts” gives this participant a sense of being “out of control”. In contrast:

I30: I needed to bring them [thoughts] back into my head. Own them, take them back on board. ... I needed to be grounded, I needed to look at bringing myself back into my body, where I’m supposed to be, where I feel more comfortable. ... I needed to just come back into myself.

“Over time”, the participant expressed “learning” to “recognise” this “ungrounded” ‘state’. This participant commented that the “only strategies” they have to “cope” with this ‘state’ were “lying down” to “recoup” their energy and “drinking water”. When this participant, in retrospect, described the experience of “not knowing what’s going on” when becoming ungrounded and not understanding their “body’s” reaction to “overwhelming” situations, they commented that this lack of understanding caused them considerable distress. The immanent structure that underpins the participant’s references to their state of groundedness is that of connection. These comments resonate with the participants who describe the “movement” of energy as the experience of being “connected” to the “universe”. Being “ungrounded” principally represents a state of disconnection from “body” and “self”. Being “grounded”, in contrast, entails connection to “body” and “self”. Although the participant above described being “ungrounded” as both “out here” or “out there” and being “out” of “touch with the universe” and the “self”, they do not give a specific location for “out there” or “out here”.

Experiences of “agoraphobia”, “panic” and “anxiety” often catch the participants by surprise. They do not, however, convey strong emotional responses to these experiences, for instance, a significant sense of fear. What is most prominent in the participants’ descriptions is the assertion that these experiences stem from a lack of energy and leave them largely unable to participate in exteroceptive doing. The participants identify these ‘correlates’ of the ‘lacking energy state’ as primarily somatic rather than psychological. They do not experience these ‘correlates’ as further limiting the energy available to them.

11.5.1.2 “Sleeping”, “Resting” and “Lying down”

Almost without exception, the two most prevalent ‘correlates’ of the ‘lacking energy state’ described by the participants are an increased need to “rest” by “lying down” and significant disturbance of sleep patterns. Most commonly, the participants claim that the ‘lacking energy state’ leads to an excessive need to sleep. A small number of participants also described the ‘lacking energy state’ as leading to an inability to sleep. In either case, the participants experience “poor quality sleep”.

I15: I'm just in a state of restlessness. So my brain, and my whole body, is just continually moving. ... I'm just so thankful when I can get still and get peace. ... It's just uncanny, my brain's just too tired to be still. ... It's just that you haven't got enough energy to sleep. If I'm having a bad time sleeping, and I'm physically feeling tired, if I gave in, rested more, went to bed and stayed there for three days, then I'd start sleeping again.

It is when the participants lack energy to the point of “exhaustion” that they experience this “uncontrollable”, “continual” “movement” of the “mind”. With respect to “sleep”, it is “movement” of the “mind” that connotes not-being-able-to-do and “stillness” that connotes

being-able-to-do. This description of movement and stillness in relation to the “mind” contrasts with the participants’ use of “movement” in their direct descriptions of energy. Here energy is required to bring about “stillness” and a state of being-able-to-do.

The only means the participants describe for achieving a degree of leverage on the ‘state’ of their energy are through “restoring” or “recharging” their energy while “sleeping”, “resting” and “lying down”. At points when the participants’ energy is “very” “low”, they describe spending as little as three hours a day out of bed, “needing” to “lie down” to “rest” and “sleep” for the rest of the day. The participants “have” “to go back to bed and sleep” and “have to” or “need to lie down flat”, to “crash on the bed”. The use of terms such as “have” and “need” convey a sense of urgency with respect to the “need” to “rest” at these times. Simple activities such as “propping” oneself “up”, “reading”, “listening to the radio” or “talking” are reported as detracting from the participants’ ability to “store up” or “recoup” their “energy reserves”. The participants do not consider “sleeping”, “resting” or “lying down” to detract from the energy that is available to them.

11.5.1.3 “Pain”, “Weakness”, “Strength”, “Stamina”, “Heaviness” and “Sex”

The participants experience various forms of “pain” (section 8.4). The form of “pain” that the participants most clearly correlate with the ‘lacking energy state’ is an “aching” sensation which occurs either in a specific area of their body, such as their “back”, “arms”, “legs”, “thighs” or “knee joints”, or throughout their “whole body”.

I1: I think as the energy leaves, I just get sore and achy.

I9: Energy’s awful, awful. You don’t have it. You don’t have any. Like I haven’t got any now, I can tell: my legs are hurting.

Examples of phrases the participants often use to describe this “aching pain” include feeling “painful all over” in which “everything seems to hurt”. Occasionally, the participants describe this aching as a “nervy aching”. The “aching” can be intermittent or, more commonly, they comment their body continuously “aches and aches and aches, a lot of aching”. Consistently, the participants express that this “aching pain” is present predominantly when their “energy levels” are “low”. The lower the participants’ energy, the more intensely they experience the “aching”.

“Weakness” and a lack of “strength” and “stamina” often accompany this “low” “energy” “aching” but are also experienced by the participants as independent ‘correlates’ to the ‘lacking energy state’.

I18: I feel so much better, just sitting or lying, than when I was standing. There’s a huge, huge difference, and I know that once I’ve sat or lain for a while, I’ll feel a lot better, in terms of the weakness. That’s a really definite thing for me.

The participants describe the “approach of weakness” as occurring with a “trickling away of energy” and describe experiencing severe “weakness” regularly. Common examples in the descriptions of this “weakness” include: “I can’t lift things”, “I can’t clench my fist”, “there’s no energy to hold a pen, I can’t grip it”, “I can’t push the toilet door open”, “my legs just don’t want to go, I have to haul myself up the stairs because my legs don’t want to work”. The participants often describe resorting to “crawling” and having difficulty with anything that required “lifting” their “arms”, such as “hanging out the washing” or “washing” their “hair”. This “weakness” made “walking”, in particular, but also “standing” and “talking” difficult and left them with a sense that they “needed” to “sit” and “lie down” to “restore” their energy.

I4: I used to be strong, but now I don’t try to lift heavy things because I know I simply won’t be able to do it, haven’t got the energy, the strength.

The “lack” of “strength” that accompanies the “weakness” the participants experience in the ‘lacking energy state’ leaves them feeling “physically powerless”, “drained of physical energy” and “limited”.

Distinct from this “lack” of “strength”, the participants describe a “lack” of “reservoir” with respect to their energy. The participants experience a “lack” of “stamina”: “stamina level is not there”, “it [energy] will not last” and, consequently, they become “exhausted very easily, very quickly”. This lack of “stamina” compounds the participants’ difficulties with “walking”, making it difficult for the participants to cover even “limited” distances.

The most distinctive ‘correlate’ of the ‘lacking energy state’ the participants describe as “coming on” when their energy is “low” is a pervasive “heaviness”.

I10: If you could imagine two people standing on either side of you pressing their hands on your shoulders and you have to get up out of the chair. But the pressure is constant. You get up out of the chair and there is no energy in your legs anyway. The sheer [effort]. It took ages to get up out of a chair. And I can’t put words to that.

I1: When I’m very tired I have this feeling of something on my chest, which I picture as a giant, and it’s pressing me down, and it’s quite hard to breathe ... moving your body around, it’s like it’s full of concrete and it’s a huge effort.

Most often, the participants describe this “heaviness” as an internal “whole body feeling of heaviness”, a feeling of being “very heavy”, “like a bus had driven over you”, as if their “limbs are very heavy”, “very sluggish”. This “heaviness” always occurs in a downward direction: “weight constantly pulling my body down”. The ‘correlate’ of heaviness is common to almost all of the participants and is described as occurring throughout the illness but is most often experienced when the participants report their energy to be at its “lowest”. The degree to which the participants felt “heavy” also related to the participants “energy level”. The “heaviness” is

strongest when the participants’ “energy level” is “low”. When they do not feel a “lack” of energy, the participants do not feel “heavy”.

A small number of participants related this “heaviness” through the analogy of interacting with an external phenomenon such as a “rock” or through the metaphor of “syrup”: “almost like moving through syrup”.

I20: Energy's just been a problem for so long. It's just something that you haven't got. You just don't have it. You put on a front, you act as though you've got energy and you put it on, and you haven't got it, you just haven't got it there. It's just not there. You know it's just not there, not there anymore. You get out and you do what you have to do, but you haven't got it there. You're pushing against it all the time, pushing as though, before you start everything, you've got to move this great rock and push it with you.

Almost without exception, the participants describe their interaction with the external phenomenon as something that they “have” to “push” against to “survive”.

Common to all the participants’ accounts of this “heaviness”, whether it is experienced as an internal or external phenomenon, is the participants’ assertion that the “heaviness” increases the “effort” required to achieve any form of “physical” action. Without exception, the participants report that “heaviness”, “pain”, “weakness” and a lack of “strength” and “stamina” are all “physical” experiences that reduce their ability to do exteroceptively. All of these ‘correlates’ of the ‘lacking energy state’ are also experienced as further restricting the availability of the participants’ energy.

Several participants commented that the ‘lacking energy state’ ‘correlated’ with a sense that they “had no energy for sex” irrespective of their desire. They did not discuss whether or not this further “limited” the energy they perceived as “available” to them.

11.5.1.4 “Food” and “Chemicals”

The affect the participants describe the ‘lacking energy state’ has on their digestion is one of the most striking “physical” ‘correlates’.

I7: It took more energy to chew food than I was getting out of it. I remember eating some food, some salad and stuff that this flatmate and I had eaten and I went to the toilet and the lettuce came out the other end pretty much like it went in. And I thought, ‘This is really scary because nothing's happening in the middle’.

The participants consistently state that when their energy is “low”, their “digestion” is “weak” and they are less able to “tolerate” foods that they find “difficult” to digest. Conversely, when the participants’ energy is “better”, they are able to “tolerate” the foods that they find more “difficult” to digest and consider that they receive more “nourishment” from the food they consume.

This relationship between “tolerance” and energy is also reflected in the participants’ experience of their response to “chemicals”. When energy is lacking, they are less able to tolerate “chemicals”.

I16: I had a wonderful afternoon once cleaning out an old clock with kerosene and polishing up the wood. I spent the next three days in bed; it just took all my energy out flat.

The most common examples of encountering “chemicals” related by the participants involved “neighbours” “spraying” for “weeds” or “pests”. The participants describe such events as “knocking” them “out” “for about three days”. This susceptibility to “chemicals” is considerably less problematic, and often completely absent, when the participants “energy level” is “higher”. The ‘correlation’ between lack of tolerance with respect to both “digestion” and “chemicals” and energy is described by the participants as further “limiting” the energy available to them and reducing their ability to do exteroceptively. The participants describe “chemicals”, the “middle” and “digestion” above as “physical” phenomena but do not make reference to any internal aspects of these ‘correlates’ to the ‘lacking energy state’.

11.5.2 “Lacking” “Emotional” “Energy”

Although the participants express that “emotions” do not seem to have a significant effect on the “flow” of their energy, they do describe “emotional” ‘correlates’ to the e-motion-al ‘lacking energy state’. The participants often refer to these emotional ‘correlates’ as a lack of “emotional energy”. In other words, a lack of “emotional energy” leads to experiences that have an emotional ‘quality’.

11.5.2.1 “Despair”, “Frustration” and “Helplessness”

The most prominent emotional ‘correlate’ of the ‘lacking energy state’ the participants describe is a feeling of “despair”.

I10: If I did some housework in one of the rooms and then when I came out of it, realised that I'd forgotten something and left something, then the energy of going back to get it, was energy I didn't have to spare, and I remember on [those] occasions feeling just total despair ... it might've been having to go back to another end of the house. It wasn't a very big house, but to get something that I'd forgotten and the energy of walking down the passageway and picking it up and coming back again to the kitchen, the energy that I would've used to do that, was enormous. And I would be in despair, because I would think, “I won't be able to get through the day now”. I'd forgotten just what that's like. I mean the despair of that was just extraordinary.

Energy is always central to the participants’ descriptions of despair. Phrases such as: “the energy of going back to get it” and “the energy of walking down the passageway and picking it up” illustrate the relationship between this despair, energy and not-being-able-to-do. Despair is an interoceptive action that is an emotional ‘correlate’ to not-being-able-to-do exteroceptively.

Consistently, the activities that the participants report despair at not-being-able-to-do are straightforward. What makes this despair so prominent is both its “extraordinary” degree and the repetitiveness with which the participants relate it.

Similarly, the participants describe a sense of “helplessness” that correlates with the ‘lacking energy state’.

I21: It just felt helpless. I don't know how to describe it. It was just like you've just got nothing left, it's just like everything has gone, just like there is not an ounce of energy. ... Just like, ‘This is too much’ and that was that feeling of helplessness.

Unlike “despair”, the interoceptive action “helplessness” is not often described in relation to a specific activity. The participants convey “helplessness” as a pervasive interoceptive sense of emptiness: “got nothing left”, “like everything has gone”. What is “empty” is the participants’ access to energy: “there is not an ounce of energy”. Against this “lack” of energy, the participants convey a pervasive “this is too much”. The participants assert that being overwhelmed occurs because the effort required to do, either interoceptively or exteroceptively, is beyond the capacity they perceive to be available to them.

Both “helplessness” and “despair” most often occur for the participants when their energy is exceptionally “low”. Such “low” ‘states’ of energy are described as literally bringing the participants to “tears”.

I1: If I’m on my feet too long, the whole system gets very near tears.

The participants convey that “tears” are an expression of not-being-able-to-do exteroceptively: “on my feet too long”. In the participants’ descriptions of these “emotional” ‘correlates’, “despair”, “helplessness” and “tears” are “whole system” experiences. Although the participants describe these ‘correlates’ as a lack of emotional energy, what underlies the lack of emotional energy is a lack of energy in the “whole system”.

The participants consistently correlate experiences of “frustration” with a lack of energy and consequent inability to “get things done”.

I7: I can remember when I was first very sick, the energy it would take me to hang up my coat was phenomenal. To lift it up, put it on a coat hanger and get it up on that thing was huge. I would push and push myself to do it. Then I just thought, “Can't do it”, which is a hard thing for people who are used to achieving things in their life. And then you have months, days and months and years go by where you can hardly do anything. There is a point where people will self-combust with the frustration of that. Well, that's my opinion anyway.

The interoceptive action of “frustration” is similar to “despair” in the sense that it arises in relation to the inability to complete what are, without exception, straightforward exteroceptive activities: “hanging up” a “coat”, for instance, or “washing your “hair”. Frustration is a ‘correlate’ that develops over time: “days and months and years”.

Not only do the participants express “frustration” at this lack of being-able-to-do exteroceptively, they also express how “annoying” it is to have to “think about” the energy even small tasks require.

I18: There is a lot of time thinking about the energy that you're using, which to me is a huge waste of time. It's annoying. Sometimes when I'm doing something, and I'm thinking, 'I haven't really got the energy to do this', so I'm much more conscious, and I get annoyed at being conscious of that.

Getting “annoyed at being conscious” about their energy is, in effect, a “frustration” with the need to negotiate the ‘lacking energy state’. Negotiating the ‘lacking energy state’ creates its own interoceptive and energetic workload.

I11: Frustrations, disappointments, hurts, or whatever, if they sit around and fester they use energy.

Several of the participants claim that the interoceptive actions despair, helplessness and frustration “use up” their energy. These emotions detract from the energy the participants perceive to be “available”.

11.5.2.2 Being “Emotionally Numb” and “Fear”

Deciding to “accommodate” or “accept” the illness, for some of the ill participants, is ‘correlated’ with their emotional energy being at its “lowest”. These participants express that they have “no energy” with which to “fight” the illness. Most prominent to these participants, but also present to some extent throughout all of the participants’ descriptions of lacking emotional energy, is the assertion that the participants become “emotionally numb” to the extent that they do not have the energy to be “frightened”.

I5: I thought, ‘Now this is really odd, why am I not frightened?’ I thought, ‘Oh, I haven’t got any energy to be frightened.’

The participants mention a “lack” of “fear” to illustrate the extent to which they feel emotionally “numb”. The pervasive sense of being emotionally numb is more often consciously described by the recovered participants. For some of the ill participants, the choice to “accommodate” the illness persists beyond points of lowest “energy”.

When “energy” is more “available”, most of the participants describe their “helplessness” and “despair” as “frightening” and relate feeling “scared” and “terrified” at their “lack” of “energy”.

I7: I didn't even have enough energy to talk to anybody, not like I didn't want to, just couldn't do it. I think the mental and emotional despair of that, I mean, I was terrified. I've never been so scared in my life.

Although the participants continue to experience a “lack” of “energy” that leaves them in “despair” and sometimes unable to “talk to anybody”, there is adequate “energy” available to support the interoceptive action of fear.

Several participants commented that “fear” about the illness was “a big energy consumer” which rendered them less able to do, both interoceptively and exteroceptively. A small number of the participants commented that “negative emotions” generally “used up” their “energy”.

11.5.2.3 “Judging” and “Suppressing” “Emotions”

Several of the participants described “judging” themselves as a “negative” “emotion” which reduced the “energy” they consider to be available to them. In the passage below, “shoulds” and “shouldn’ts” refer to “judgements” originating from “many different sources”.

I21: Shoulds and shouldn’ts and they come from my childhood, they come from, wherever, but they’re all internalised and they’re all related inside and they do bring the energy down.

With the phrases “internalised” and “related inside”, the participant is making direct reference to interoceptive actions involved in “judgement”. Judgement is an interoceptive action that the participants claim arises more often when they lack energy. Several participants claim that the interoceptive actions of “judgement” “bring” their “energy down”. Again the movement of “energy” is downward.

Speaking from the perspective of recovery, one participant observed that some of the occasions on which they were “energetically drained” or “tired” were also the occasions on which they were “suppressing something emotional”. For this participant, “suppression” seemed to “have quite a direct line with my energy”. This “direct line” is also expressed in the “unblocking” or “freeing up” of “energy” when the participant is able to “resolve” the “suppressed” “emotion” by “sitting with it” and “acknowledging it”.

I21: If I can sort of understand and be gentle with whatever’s gone on to start with I don’t tend to get into that downward spiral. To get past that was just to really sit with what was going on for me and just allow whatever was happening. Not necessarily to understand it, but to be with it and to give it its place and then it kind of seems to release again. ... I guess that’s why I do it, because it will change. I know it will change if I stay with it and usually it’s freeing, it’s like it’s an unblocking of the energy. It’s freeing, but if I go into it with the intention that I want to free it, that won’t necessarily do it. That is why I just have to sit with it.

“Suppression” is a complex interoceptive process. This participants’ description of negotiating “suppression” is unusually rich in references to other interoceptive actions: “understand”, “be gentle”, “downward spiral”, “get past”, “really sit”, “allow”, “be with it”, “give it its place”, “release”, “change”, “know”, “freeing”, “unblocking”, “go into it”, “intention” and “sit with it”. Central to this interoceptive process is the desire for “change”. Change comes about in this

account, not through the effort of action but, instead, through the stillness of “allowing”. For this participant, it is through being-able-not-to-do that the “unblocking” of “energy” and the “freeing” of “emotion” occur. This is similar to the participants’ comments with respect to sleep.

The account above contrasts with an ill participant’s sense that, although the ‘lacking energy state’ forced her to “let go” of “emotional baggage”, this did not last. As soon as the participant’s energy returned, she “picked up” the “emotional baggage” “again”.

I5: That was funny. I really thought perhaps I was dying and they just bubbled up and I thought, ‘Okay, you know, that's silly being resentful about that’. It was family stuff again and I thought, ‘Just let it go’. And it was easy to let it go because it took too much energy to hold onto it and I realised that resentments and bitterness [were] causing all this and I thought, ‘Yip, it's dead right’. But sometimes you’ve got to be made aware of it. You have to become aware of it. And then, somehow, let it go because knowing it’s up here [referring to head] isn't always letting it go either, is it? Somehow you’ve got to find some mechanism to let it go, and the fact that I was so ill, my body had to let it go. But as I said, when I got better [it] started back up, I realised that I'd picked them up again, which was very interesting.

Both of these accounts relate that “suppressing” or retaining a “hold on” an “emotion” requires “too much energy”. Both accounts describe “emotions” “releasing” or “letting go”. In the second account, the lexemes “made”, “have”, “had” and “got” in phrases such as “made aware of it”, “have to become aware of it”, “got to find” and “the fact that I was so ill, my body had to let it go” communicate compulsion. This compulsion contrasts with the first account which, conversely, communicates the need not to have “the intention that I want to free it”. In the first account, it is the “I”, the ‘self’, that becomes “free” from the “emotion” whereas in the second account it is only the body, “my body”, that “releases” the “emotion”. These differences suggest that the participant in the second account is positioned in some sense more passively with respect to the ‘self’ and the ‘letting go’ of “emotion”. Both these accounts of “suppression” and the participants’ accounts of “judgement”, however, take the causal relation between “energy” and these “emotions” in the opposite direction to the majority of the participants’ experience. In these cases, the interoceptive processes of “judgement” and “suppression” are understood as causing the reduction of “energy” rather than the ‘lacking energy state’ causing an inability to do through emotional ‘correlates’. This apparent divergence of explanation with respect to “judgment” and “suppression” does not imply that these accounts are necessarily more adequate.

Consistently, the participants claim that when their “energy” is more adequate they have more “emotional energy” and they do not experience “despair”, “helplessness” and “frustration” to the same degree. The participants claim that “negative” “emotions”, including the thymic processes of “judgement” and “suppression”, have less “impact” on their “energy” when their “energy” is more adequate.

11.5.3 “Lacking” “Mental Energy”

Just as “energy” can take on the ‘quality’ of the pragmatic or emotional, the participants also relate the cognitive ‘quality’ of “energy” as “mental energy”. When the participants are referring to this ‘quality’ of “energy”, they most often use the lexeme “mental”. However, the participants use the lexemes “mental energy”, “psychological energy”, and “intellectual energy” interchangeably. The participants describe lacking “mental energy” as one of the most “distressing” ‘correlates’ of the ‘lacking energy state’.

The most commonly related ‘correlate’ of lacking “mental energy” described by the participants is “fuzzy thinking”, a “wooliness” or “cloudiness in the head”.

I21: Low energy ... that sort of cloudiness in the head I'd get at times, that sort of wooliness, not feeling sharp, not feeling right there.

Consistent with the other ‘correlates’ of the ‘lacking energy state’, this “brain fog” or “foggy head” is most predominant when the participants’ “energy levels” were “lowest”. In the participants’ experience, it becomes easier for them to “think clearly” when their “energy” is more adequate. “Clarity” of thought represents the ability to do interoceptively, whereas “fuzzy thinking” is described as an impediment to interoceptive action.

The majority of the participants express the perception that when their “mental energy” is “low” their “brain slows down”.

I5: I remember one other time picking [up] a potato and thinking, “Now what do I do?” My mind just seemed to slow down so much that I had to make that cut there and then I had to turn it and make that cut there ... if I'd had the energy, I'd have been scared. I'd given up driving because I couldn't trust myself to make a decision because my brain worked so slowly. I mean physically driving the car was still second nature but it was making the judgement calls and I wasn't prepared to put myself or other people at risk for that.

“Slow down” and “worked so slowly” convey a lack of cognitive interoceptive action and movement. In contrast, a small number of participants describe their “thinking” as becoming “restless” when their “energy” was “low”. In these cases the participants’ ‘correlate’ the excessive movement of “restless thinking” with the ‘lacking energy state’. This not-being-able-not-to-do prevents the participants from “thinking straight”.

Other ‘correlates’ of lacking mental energy the participants described included “difficulty” with “organisational tasks”, “remembering”, “talking straight”, “finding and saying words”, difficulty with “focus”, going “blank” and the tendency to “slur words”. The participants describe these ‘correlates’ of lacking mental energy as an inability to “think” and “organise” their “thoughts”.

The participants describe “noise”, “bright light” and “messy” or “chaotic” environments as “over-stimulating” and they claim, consequently, they do not have the mental energy to “cope”

with this stimulation. Activities the participants commonly describe not “having” the mental energy to do include “listening to the radio” and “watching television”.

With these mental ‘correlates’, the participants communicate their experience of “lack” with respect to cognitive interoceptive action. The participants consistently claim that all of these ‘correlates’ of lacking mental energy are most prevalent when their “energy” is “low” and often disappear completely when their “energy” is more “available”.

All of the participants describe “communication”, both “listening” and “talking” to others, as “difficult” when either their emotional energy or their mental energy is low.

I1: There's no energy there to cope with it. Like, I think the brain stuff needs heaps of energy. And talking, to me, is one of the most tiring things and that includes listening and understanding what the other person is saying. Sometimes [you] can't find a word, you're so tired that you can't either say it or find it in the first place. So it all slows down.

What is common to all of the participants’ descriptions of the difficulty they have with “communication” is an emphasis on the relative cognitive complexity that they perceive this activity requires. Lacking mental energy means that the participants are unable to engage in complex cognitive interoceptive tasks. All the ‘correlates’ of lacking mental energy and, most particularly, this inability to “communicate” leave the participants “feeling” “vulnerable” and with a particular sense that they cannot “communicate” their illness experience. In this respect, “lacking” “mental energy” connotes not-being-able-to-do interoceptively and highlights the significant loss of “world” in which to do that a lack of interoceptive action implies. The participants do not describe any of the ‘correlates’ of lacking mental energy as further reducing the energy available to them.

11.6 “Energy” “Management”

11.6.1 “Limited” “Energy”

Throughout the participants’ narrative expression of the ‘lacking energy state’ (section 11.4) and its ‘correlates’ (section 11.5), “energy” is presented as “precious” and “limited”.

I20: Frail, exceedingly limited energy-wise, food-wise, limits, terrible limits on me in every way. I just can't do anything very much. I can go out in the mornings and, as a rule, I'm feeling as good as I ever get and do my shopping and things and come home and have my lunch and then the rest of the day, I don't want to go anywhere else. So I'm very limited in energies. I just can't stand any strain of any sort.

Apart from the lack of energy described by the participants, what also makes energy “limited” is the “sudden” and “unpredictable” manner in which energy changes. In response to the experience of “limited” “unpredictable” energy, the participants describe various ways in which they try to “manage” their “energy”.

The majority of the participants describe taking considerable steps to avoid “overextending” their perceived “energy limits”. They present a conflict they experience between “pushing” and “not pushing” their “limits”. They describe this tension as akin to the experience of walking a “tightrope”. Some of the participants describe “testing” for the “limit” of their “energy”: “testing just to see where I could push and how long I could push for before it all came down around my ears”. Most of the ill participants commented that they were not prepared to “test” this “limit”: “these days I don’t push myself to that limit”. Some of the participants simply expressed recognising when they had been “pushing” this “limit”: “I’ve really been pushing myself”. Without exception, the participants treat the “limit” to their “energy” with caution: “never walk a tightrope without a safety net”. Several participants express experiencing the conflict around their “energy limits” as a process of “adjusting” to the “restrictions” created by “limited energies”.

I11: I found it very difficult to learn to deal with the restrictions brought about by having no energy to pursue my interests, having to alter what I was doing to fit the pattern of the energy that I had.

All of the participants describe “energy limits” as “difficult” to “manage” and adhere to and many of the participants claim that having to “manage” such “limits” is a “new” experience. The participants convey compulsion, a “having to”, with respect to “managing” these “limits” because they “can’t stand any strain” on these “limits”. The total amount of “energy” the participants perceive to be available to them is finite and they understand this as creating restrictions or “lack”. In response to this “lack”, the participants attempt to find ways to make their energy predictable. The isotopes that emerge in the participants’ descriptions of “limited energy” are finitude and predictability.

11.6.2 The “Minutiae” of “Energy” Analysis

The most common way the participants narrate their experience of the “limits” on their “energy” and the means by which they try to make their “energy” predictable is by continually relating the detailed, mechanistic analysis of the “energy” requirements of the “minutiae” of “doing ordinary things”. The participants describe this analytic process as the “need” to consider the “energy requirements” of “ordinary activities” on a “minute scale”, “needing” to consider “the most micro individual thing”. “Need” conveys compulsion.

Almost all of the common “physical” movements the participants describe as “difficult” involve raising the arms: “the energy it would take me to hang up my coat was phenomenal. To lift it up, put it on a coat hanger and get it up on that thing”. The next most common movement

the participants have difficulty with is “standing up”: “just getting up out of a chair, getting out of bed in the morning, it just required an enormous effort, just to get up, then to stand up”.

The most common “everyday” “minutiae” or “ordinary things” the participants relate include “showering”, “getting dressed” and food preparation.

I18: I'll have a really bad day and it's a huge effort to get up and get into the shower. It's a huge effort even just thinking about it. I'll start off having a shower and, particularly if I have to wash my hair, standing and raising my arms to do that makes me really tired and I start to feel really weak and so, often, I'll actually sit down. Turn off the shower, sit down to wash my hair etc. etc. and just stand up for a while to rinse. Other times, I'll have the shower but as soon as I get out of the shower, I sit down. So, I'm sitting, I put a towel down obviously, sitting on the tiles in the bathroom, for up to ten minutes before I've got the energy, the strength, really, to walk back to my room. I know what it is with washing my hair: it's the raising of my hands, and maybe just standing still. I guess standing still is a lot harder than walking.

It is noteworthy that in these descriptions the participants attempt to detail not only every exteroceptive action required to complete a task but also the interoceptive actions involved. It is the sum of both the interoceptive and exteroceptive actions that represent the “effort” or “energy” required to complete the activity in question.

Often in these descriptions, the participants focus on complex interoceptive actions such as making decisions: “if you go to get a weed and you miss it for some reason or it gets stuck in the ground, is it really worth it, really getting it out or just leaving it until another time”. Through this examination of the “minutiae” of “everyday things”, the participants attempt to find the most “efficient” use of their “energy”: “I use a stool instead of stand, I read lying down ... because it allows me to not have to use the energy and the muscles of sitting up”.

The participants comment that they are aware “others” find this attention to “minutiae” challenging to “hear” and “understand”. The participants themselves claim that the “need” to “think” about activities at this level is “frustrating”, “annoying” and “restrictive”.

I27: It's quite restricting ... you end up doing very little at all, because, it just takes so much out of you to just brush your teeth or, just, go for a shower. It was your whole day's worth of energy, and that was it. So, you couldn't actually do anything else. It's not particularly life-giving, such a simple task as that, it's maintenance, it's not enjoyment.

Although the participants consider this attention to “minutiae” necessary for their “survival”, they do not take pleasure in the analytic process; rather, they consider this compulsion a “burden”. Neither do the participants take pleasure in the activities that they analyse in this way. They describe these activities as “maintenance”: they do not find them “life-giving”. This analytic process “adds” to the “energy” available to the participants only with respect to the “energy” that it allows them to avoid using. In all other respects, it is negatively evaluated by the majority of the participants.

11.6.3 “Energy” Analogies and Metaphors

A small number of the participants frame this “management” of “minutiae” more positively. These participants describe “energy” “management” through the analogy of “needing” to develop a “new” “language” and “a whole new relationship to energy”, consistently claiming that this is something they “never” needed to consider prior to illness. This new “language” or “new relationship” to “energy” requires that the participants reassess their “concept” of “energy”: “the concept of energy is something that is expanding in my consciousness the whole time”.

The participants describe this interoceptive analytic process as learning to understand “how” they “use” their energy, “how” to “make decisions” about how to “expend” their energy and how to “fine-tune” their activities so that they “use” their energy as “productively” as possible.

I5: I've just had to learn different strategies for getting more out of my body, out of my mind and out of my day, basically. And it's been a very gradual process of looking at every little thing, just being aware of what takes energy and what doesn't ... inch by inch over four years, noticing every moment.

The participants become interested in which activities and objects provide them with “energy” and which seem to “detract” from their energy.

I5: I started noticing where I feel like I'm getting energy, where I feel like it's going. When I was real sick, I just thought it was all me, leeching out. But I have come to realise that certain things give you energy and certain things take it away. When you [have] got none you [have] got to be really rigorous about not letting any one take that one drop that you've got.

The participants describe “learning how” to “balance” their “energy” by “trying to plan” to “have” energy. In order to plan to “have” “energy” for an activity the participants attempt to keep track of “how much” energy they “have” by expressing this either as a percentage or on a scale of one to ten. The participants use this rating to decide how much they will attempt to achieve. Often the participants describe aiming to complete “fifty percent” of what they imagine they are capable of.

I13: If I wake up and I'm having a good day and I've got a list of things that I would like to do that day, I have a cut-off point, halfway mark, and I'm really good now. I stop at the halfway mark and I conserve the rest of my good energy for the rest of the day and hope that that good energy will build up and I'll have more good days than bad days.

One participant describes this process as “energy management”, concluding that this is the “crux” of “learning to live” with the illness.

I11: It's all energy management. The whole thing in my view about living with this illness, once you get past all of the specific physical symptoms that you have to deal with, and

getting through all of the learning to deal with the cognitive difficulties that come up, dealing with the emotional stuff ... that is where the crux is and that is all energy management.

A common analogy the participants use to describe their “limited energy” is to consider that they have a “daily energy allowance”, a “limited” “daily energy package”.

I21: All your energy comes out of one basket and so your emotional energy, physical energy, your mental energy all have to come from the same thing. So, just to be aware of all that.

The participants consider that all of their activities are competing for some of the energy in this “finite basket”. This “energy package” is ‘closed’. Whether it is “energy” with a “physical”, “emotional” or “mental” ‘quality’ that the participants are “managing”, the total amount available to them in the ‘lacking energy state’ remains finite.

Two common metaphors the participants use to describe this “energy basket” or “energy package” are to refer to it as a “reservoir” or “battery”.

I5: There just seems to be a reservoir, sometimes, and it just comes out, and other times there's not. And I'm never quite sure how quickly it's coming out. Sometimes it's used very quickly and other times it really surprises me that I've still got this energy.

I25: The only way I can describe it is it's like a battery. It's like your getting plugged in, and then it's taken out and it's like it ebbs out of you and you can't do anymore. Your body, it's just like coming up against an invisible wall and I tell you, you just can't go beyond that limitation. I mean it's just your whole body ... flat.

Being “unpredictable”, how much “energy” is available to the participants from their “battery” or “reservoir” is never easy for the participants to assess: “sometimes it's used very quickly and other times it really surprises me that I've still got this energy”. The participants also express a sense that they cannot “negotiate” the amount of “energy” that is available to them: “you just can't go beyond that limitation”.

To “manage” their “limited energy”, the participants describe needing to “conserve”, “reserve” and “preserve” the energy in their “battery” or “reservoir” so that they can “build up” or “store up” this energy.

I22: One of the ‘prescriptions’ is to conserve your energy: don't push yourself, don't feel guilty, if you have to rest. Then the learning curve was to learn how to do that without feeling bad about it. To learn that it's fine to lie around and read and let your body heal itself a bit and let your body build up some energy. So that was the learning curve, because I'd never, I mean, everybody sort of learns the opposite I think.

Some of the participants describe “learning” to “rest” by identifying and choosing to participate in restful activities that “built up” or “charge up” their “energy”. Without exception, these participants describe this “learning” as a new experience. None of the participants name an external source from which the “energy” that is “recharging” originates. Neither do they provide any explanation for how the “energy” that they are “conserving”, “reserving” or “preserving”

might create an increase in the “energy” available to them. All of the activities the recovered participants describe as “recharging” have a meditative component (section 10.5.2).

A small number of the participants analysed their “energy” consumption through selected economic metaphors, where the “currency” was their own energy. They described needing to “budget” their energy in “cents” where “others” were “budgeting” in “dollars”. These participants expressed concern that potentially they would “pay” a “high interest” on any extra energy they “used” if they tried to “push” their “boundaries”.

I20: You know that you're using reserves that you just can't afford to use, you're in debit. Like you've gone into overdraft. You know that you're going to pay for it. There'll be a high interest on it.

“Pushing” the “boundaries” would “cost” them a “high price” and could mean they “risked” ending up “in debit”, “overdrawn” or in “overdraft”.

I11: What this will cost me is my afternoon. So that's a choice in a way, of doing things. I look at my entire life as an enormous cost benefit analysis. What do I want to do? What benefits will it bring? How much is it going to cost? Is it worth it?

These participants describe trying to estimate how much activities might “tax their “credit”. Wanting instead to “save up” their “energy” so that it was like “money in the bank”, the participants describe wanting to “maximise” their “outcomes” by engaging in a constant “cost-benefit analysis” and deciding whether activities were worth engaging in based on the “return” they would receive on the “investment” of “energy” those activities would require. None of the participants refer to an “investment” of “energy” as a means to increase the “energy” available to them. Equally, none of the participants refer to any ways in which they might create value within this “currency” system. Like the “energy package” analogy, this “currency” represents a ‘finite’ ‘closed’ system.

Whether the participants are referring to an “energy package”, “allowance” or “basket”, “reservoir” or “battery” or drawing upon selected economic metaphors, all of these descriptions illustrate the isotopy of finitude and the sense of restriction it implies. What the participants are attempting to achieve through these analyses is a degree of predictability with respect to the availability of their energy. Nowhere within the energy narrative do the participants provide any singular spatial location for energy. It is not exclusively located within either the exteroceptive or interoceptive aspects of the participants’ experience and the location of energy in relation to the ‘self’ is particularly unclear. “Energy” is dis-located.

The participants describe in considerable detail what energy does and what energy enables. This gives energy a certain agency. The participants do not describe how, as a subject in relation to energy as an object, they might do energy. This gives the impression that the participants are

passively positioned with respect to access to energy. Metaphors such as “saving up” or “recouping” energy reinforce this passivity. What is strikingly absent from the participants’ narrative on energy is any explanation for how energy might be generated or created. This would require the participants to engage an active and reflective position with respect to energy, whether energy was subject or object. Notably, several of the participants mention that physical activity does not increase their energy.

Although the participants’ energy narrative clearly articulates the understanding that energy transforms, the participants do not present any explanations for how energy transforms. Although the participants describe energy as “universal” and correlating to “physical”, “emotional” and “mental” experiences, they do not provide any explanation for how “universal” energy might transform into, exchange with or ‘correlate’ to an “energy” of another quality. This is particularly obvious in the participants’ discussions of “energy” “flowing” or “draining” as the participants do not describe where energy “drains” to or where “energy” is “flowing”.

11.7 “Energy” and “Recovery”

All of the recovered participants described the “return” of their “energy” as a “very gradual”, “inch by inch” “process” which “slowly but surely” involved a “steady build-up” with the occasional “little dips”. Many of the participants who had recovered in recent temporal proximity to the interviews expressed a lack of “confidence” with respect to their energy. These recently recovered participants claimed that their “energy” remained more “fragile” than they recalled it to be before becoming ill.

I9: I’ve got more energy, more get up and go and get things done. Although, as I said, I do tire very easily, whereas I didn’t before. ... You just haven’t got the same amount of energy. That’s what I find, so you sort of just push on.

The recently recovered participants report continuing to experience “fluctuations” in their energy and they regard these as distressing.

I28: That is very frightening, to have those spells. It’s like somehow you still live under the threat of ME, like you can’t quite escape it.

In “those spells”, when the recently recovered participants’ energy “fluctuates”, it becomes “low” or “lacking” and this “threatens” to produce a return of the illness. Participants who had recovered some time before the interviews expressed more confidence in their energy.

11.8 Analysis

The participants’ narrative on “energy” is central to their discourse on the experience of CFS. “Energy” acts as the epistemological subject that expresses the fundamental problematic

underpinning the participants’ experience of CFS. The “energy” narrative is a narrative quest for “energy”. “Lack” is eliminated through the bringing about of conjunction between the subject and the object of desire. In the narrative quest for “energy”, “energy” is the object of desire. Given the abstract quality of “energy” within the “energy” narrative, it is important to note that this object is not a thing. Rather, “energy” implies having an ability: the ability to do. What is at stake with respect to “energy” is the participants’ competence in relation to all forms of action. The ‘lacking energy state’ amounts to the participants’ experience of a lack or absence of competence to some degree (section 11.4). This leads to numerous experiences of stasis. In contrast, the ‘having energy state’ amounts to the participants’ experience of having an abundance of competence and ability to transform (section 11.3).

Links three through seven of the binding chain of causality were identified as referring to competence (section 9.9.4). These links could be considered a description of the qualities required for competence. A disruption within any of these links would, accordingly, lead to an inability to establish competence.

It is important to consider the extent to which the participants’ experiences of “energy” refer to the sixth link, contact¹¹⁰. It is possible, for instance, that the participants’ descriptions of the ‘having energy state’ refer to an abundance of contact and their descriptions of the ‘lacking energy state’ to a lack, in varying degrees of intensity and pervasiveness, of contact, or some aspect thereof. If it were the case that “energy” is, in fact, a reference to contact, then it would be fair to suggest that this would be borne out in the ‘correlates’ to both the ‘having energy state’ and the ‘lacking energy state’.

With respect to action, contact is the key link within the binding chain of causality and particularly within the five links related to competence because, in order for action to be viable, it must be responsive to the environment and contact is the process by which structural coupling between cognitively directed action and the environment is established (section 4.14). Contact is at the basis of the emergence of a moment of mind. As a process, contact takes sense data (the object) and binds this sense data to an experiencer (the subject) of a basic element of conscious experience (section 4.10). The links’ dispositional formations, craving and grasping, and the mental factors perception, intention and attention together create becoming and birth; that is, action is produced from the basic elements formed by contact. What emerges out of this “soup, the entire organism in situation” are the emergent properties of mind, such as memory, emotion and reason (Varela 1999a, p.78) (section 4.15). These emergent properties cannot be considered

¹¹⁰ “Having the six senses means that each sense is able to contact its sense field, its appropriate object. Any moment of consciousness involves contact between the sense and its object (contact is an omnipresent mental factor ...); without contact, there is no sense experience” (Varela, Thompson, and Rosch 1991, p.113).

discrete from this “soup” or from each other, and, therefore, it is reasonable to presume that if contact or some aspect of contact is impaired or disrupted so, therefore, emotion, cognition and enaction will also be impaired or disrupted.

It is plausible to suggest that the participants’ experiences of “lacking mental energy” are, in the majority, descriptions of a lack of contact with consciousness (section 11.5.3). Contact with consciousness could be described as an experience of one’s internal world. The participants specifically mention losing aspects of this “world”. This includes the ability to consciously process strong sense stimuli such as “noise”, “bright light” and “messy” or “chaotic” environments. In contrast, the participants’ experiences of “clarity” could suggest the return of contact with the senses and the consciousness with which to process them (section 11.3.1). It is reasonable to suggest that the participants’ difficulties with “talking” and their experiences of “slurring words” could express a lack of contact with the kinaesthetic aspect of touch.

A lack or disruption of contact with kinaesthesia could also offer an explanation for the participants’ experiences of “aching pain”, “weakness”, a lack of “strength” and “stamina” and the participants’ experience of “heaviness” (section 11.5.1.3). In contrast, the participants’ experience of “spontaneity” could reflect a strong degree of contact with kinaesthesia (section 11.3.1). The participants perceived need to “sleep”, “rest” and “lie down” could be the cumulative effect of a loss of contact with kinaesthesia (section 11.5.1.2). The urgency with which the participants perceive this need to rest may reflect the degree to which they have lost contact with kinaesthesia.

The participants claim that experiences of “agoraphobia”, “panic” and “anxiety” occur when they are “pushing” the “boundaries” of their “physical energy” (section 11.5.1.1). If the participants lack contact with the senses and are, therefore, unable to accurately assess their proprioceptive state, it is possible that these experiences could be the result.

The description of “ungroundedness” presented by one participant could be considered a description of the experience of losing contact. This would be consistent with the assertion made by some of the participants that the movement of “energy” within the ‘having energy state’ provides them with a sense of connection. In effect, groundedness and connectedness may express contact where ungroundedness and disconnection express a lack of contact (section 11.3.2).

Similarly, if the brain is involved with the processes of digestion and excretion in such a way that contact is required, the difficulties the participants experience with “food” and “chemicals” could be the effect of a lack of contact (section 11.5.1.4).

An enactive approach to cognition would imply that a loss or disruption of contact with the senses directly or with the second aggregate component of consciousness would disrupt the emotions (Varela 1999a, p.78). It is reasonable to suggest that the participants’ descriptions of feeling “emotionally numb” could be a description of the experience of such a disruption (section 11.5.2.2). It is reasonable to suppose that the experience of the ‘lacking energy state’ would have its own emotional impact and that emotions such as “despair”, “frustration” and “helplessness” would result (section 11.5.2.1). The participants describe “helplessness” as a pervasive “emptiness” with respect to “energy”. It is interesting to consider to what extent these three “emotions”, but particularly “helplessness”, like feeling “emotionally numb”, could be articulations of a loss of contact. The “emotional” ‘correlates’ of the ‘lacking energy state’ are all negatively evaluated and become proportionally more predominant as the participants’ access to “energy” reduces. It would be interesting to consider why such a preponderance of ‘negative’ “emotion” arises in this circumstance. Is it possible, for instance, that certain mental factors are more persistent than others and that these give some advantage to the organism?

In the ‘lacking energy state’, “energy” becomes “blocked” or moves “out” of some aspect of the participants’ experience (sections 11.4.1 and 11.4.2). This could be a description of the experience of contact reducing or the inability to establish contact. Perhaps what is unique about the participant who asserts “potential energy is still there” is that this participant is observing that contact can be re-established, where the majority of the participants do not perceive this potential. The “unpredictability” of the availability of “energy” could reflect the experience of contact that changes unpredictably. This interpretation of movement within the ‘lacking energy state’ would be consistent with the suggestion that the “ease” with which “energy” “flows”, provides competence and promotes performance and transformation in the ‘having energy state’ is the experience, in the context of CFS, of an abundance of contact (section 11.3.2). Concurrently, contact would connote “health” (section 11.3.3).

Perhaps the participants’ attempt to describe “what energy is” as an abstract, “ubiquitous”, “universal”, “intelligent”, ‘life-giving’ ‘field’ which they experience only in relation to another aspect of their experience is their attempt to articulate their direct perception of contact (section 11.2). This could illuminate the participants’ difficulties with respect to locating themselves within this ‘field’ and the lack of location for “energy” within the “energy” ‘states’. If an “energy” ‘state’ is a state of contact, absence and presence are perhaps more apt terms in which to describe its experience than any sense of reciprocal permeability. The concept of reciprocal permeability would suggest a paying attention to a broader ‘field’, one that includes the relation between interoceptive and exteroceptive experience.

The participants' descriptions of "energy" "management" provide numerous examples of their attempts to become aware of their experience of "energy" (section 11.6). The three gestures of becoming aware are highly interdependent. Becoming aware of the content of L1 requires L2, the suspension and redirection of normal mentation. Redirection requires suspension and in order to return to suspension, one must let go of redirection. In enactive terms, the gesture of letting go requires a light touch: it cannot be achieved in a heavy-handed manner. L1 represents the lived content of experience, in other words, that with which we have contact. Redirection of mentation requires contact with the contents of consciousness. Letting go is the gesture required in order for there to be any change in that aspect of consciousness toward which attention is directed. Letting go cannot be achieved if any hold is retained on L2, redirection. In other words, letting go cannot be successful if grasping is limiting the aspects of consciousness within attention.

The analysis of the participants' descriptions of "energy" "management" suggests that the participants are grasping after the establishment of predictability within their experience of "energy" (section 11.6). This grasping may be limiting the aspects of consciousness within attention and potentially preventing the participants from letting go and observing aspects of experience important to the establishment of contact. By its very nature, grasping entails the enactment of criteria. These criteria focus and limit attention especially when certain observations would require actions outside of the scope of expectation.

A lack of letting go could provide some explanation for the participants' experiences of poor quality sleep and an inability to sleep (section 11.5.1.2). Likewise, the participant who reports successfully resolving "suppressed" "emotions" through conscious "allowing" may be an example of letting go (section 11.5.2.3). Despite describing their experience as "letting go", the participant who "picked" their "emotions" "up again" may have only experienced a loss of contact with these emotions.

If the participants' descriptions of "energy" are, in fact, descriptions of the experience of an aspect of contact, then this is consistent with a lack of a generative concept with respect to "energy". Contact is a process that happens in every moment of consciousness and need only be observed; however, observing contact requires the gesture of letting go and is therefore prevented by grasping. What remains is to ask the question: why do the participants experience a lack of contact? Does this lack of contact relate to the participants experiences of sanction? If so, what does this convey about the intersubjectivity of contact?

11.8.1 Efference, Afference and the 'As-If-Body-Loop'

Tsakiris and Haggard (2005) draw on Gallagher's phenomenological distinction between a sense of agency, which is characterised by intending and executing an action, and a sense of

ownership, which refers to the experience of sensation. Ownership principally involves afference¹¹¹ as sensation that is largely peripherally generated whereas agency principally requires efference¹¹² since agency is centrally generated. The authors comment:

In the “Williams debate”, W. James argued that knowledge of our movements originates from peripheral information, whereas W. Wundt emphasised the role of a central corollary efference of the motor command. Traditionally, proprioception is conceptualised as the modality of the self *par excellence*, especially in relation to body awareness, because proprioceptive information unambiguously pertains to the sensing subject. On the other hand, efferent information and the function of the internal models of the motor system have been linked to the sense of agency. These two sources may produce the distinctive phenomenologies of the “sensory self” and the “acting self” respectively. Although the “Williams debate” originally concerned the representation of actions, it has wider implications: is the “self” primarily a *proprioceptive* experience of our bodies, or primarily a *motor* experience of our actions? In an attempt to answer this question, we will review experimental evidence that highlights the phenomenological and functional differences between the “acting self” and the “sensory self.” The “acting” self is the author of an action and also the owner of the consequent bodily sensations that were not intentionally generated, but on the contrary were passively experienced (Tsakiris and Haggard 2005, pp.388-9).

Tsakiris and Haggard (2005) put forward a model of agency based in their experimentation and review of existing literature within three research programmes: sensory suppression, time-awareness, and self-recognition. With respect to sensory suppression, they conclude that:

Intention and efference act as a general context for awareness, shifting the perceived intensity by fixed amounts. This context effect could be applied predictively in the form of a “sensory bias.” We have shown that this bias occurs quite generally, even when the details of the action do not predict the details of its sensory consequences. The mere intention to act would therefore be sufficient to apply this bias. Sensory suppression may be an important index of agency. Our sensory suppression results suggest that the sense of agency could arise at an early stage in the planning of action, and before the precise details of the impending movement are determined (Tsakiris and Haggard 2005, p.393).

In other words, agency may be derived from processes involved in the appraisal of action. This implies that inaccurate appraisals would impact on agency. Sanction is such an appraisal process. With respect to time-consciousness, they conclude that:

In summary, by manipulating both causality and agency, we showed that the perceived times of voluntary actions and their effects are bound together. The results reviewed provide support of the existence of a CNS process that operates only when a subject is the active agent of her actions. This “intentional binding” process integrates the conscious representations of actions and events. A series of experiments have consistently shown that this process is specific to actions, thereby underlying its intentional nature, and does not reflect general perceptual attraction. This “intentional binding” mechanism might underlie the way in which the mind constructs a strong association between intentions, actions, and consequences so as to generate the unique and private phenomenological experience of self-agency. (Tsakiris and Haggard 2005, p.396)

¹¹¹ “Afferent: designating nerves or neurons that convey impulses from sense organs and other receptors to the brain or spinal cord, i.e. any sensory nerve or neuron” (Martin 1994, p.13).

¹¹² “Efferent: designating nerves or neurons that convey impulses from the brain or spinal cord to muscles, glands and other effectors; i.e. any motor nerve or neuron” (Martin 1994, p.207).

Again, these findings with respect to “intentional binding” show that agency, and further the self, are related to action. With respect to self recognition, they conclude that:

Interestingly, efferent information has a significant contribution not only in the conscious and/or unconscious processing of various aspects of action *per se*, but also in the perception of the effects of the action. Thus, in this experiment, the movements of the right hand, which subjects used to recognise themselves, were not actions but rather the effects of an action performed by either the subject or the experimenter on the other end of the lever. This is consistent with recent experiments on action recognition and prediction, where an authorship effect was observed in recognising and predicting actions that were performed by the participants themselves, when compared to actions performed by other agents. This finding suggests that efferent information might also be important for self-recognition and self-awareness, and not only for motor control. This distinctive role of efference in self-recognition experiments suggests that central signals are highly accurate in detecting the appropriate afferent signals that pertain to one's self, and that even though the content of our body awareness is mostly afferent in its origin, it is nevertheless modulated by efferent-driven processes. (Tsakiris and Haggard 2005, pp.401-2)

In sum, what these findings suggest is that, although proprioception has long been recognised as intrinsically linked to bodily self-awareness, the importance of efference has not been fully understood. The authors suggest that:

Overall, the “agentic self” seems to be constituted by voluntary movement, and it is experienced as a “perspectival source” that modulates the phenomenal experience of peripheral and central signals. Our results suggest that this sense of agency is efferent-driven, whereas the contents of body awareness may be predominantly afferent in their origins. At the beginning of this paper we argued for a methodological separation between “acting” and “sensory” self. This distinction can be implemented by dissociating efferent and afferent information in order to investigate the interplay between these two sources in self-awareness. Efference intrinsically modulated the perception of afferent events. This is not surprising since normally we actively explore our environment, rather than passively perceiving it. The body is only rarely an object of perception; it is normally a subject. In that sense, body awareness is not simply another form of object consciousness. Models of self-awareness based on the privileged nature of proprioception as the “sense of self” ignore the mere fact that my body is not so much an object of perception, but rather it is given to me as a subject; it is my being-in-the-world. And this might be so because, in both phylogenetic and ontogenetic terms, perception and cognition begin with movement (Tsakiris and Haggard 2005, p.404).

In terms of proprioception and the external senses, efference and afference could be considered to be the neurological mechanism of contact. For the present research, it would be important to consider how the participants' discourse on CFS may suggest a breakdown of some sort in efference and/or afference, and therefore in contact, at the time of the onset of the illness, a breakdown that might persist past the onset of the illness and only mend much later. It would also be important to consider the relationship such a breakdown would have to action.

Treisman (2003) provides a review of the process referred to as binding, the process that connects various perceptual events such that they become consciously available. As such, binding involves not only contact but also discernment, attention and possibly feeling. Cotterill

(2003) examines the importance of action in the generation of consciousness and its unity. Although binding is broader than contact, investigating the relation between binding, the unity of consciousness and action may provide an explanation for the participants’ experience of “energy”.

Antonio and Hanna Damasio (Damasio and Damasio 2006) have recently reviewed emerging neurological and physiological evidence for Antonio Damasio’s ‘as-if-body-loop’. The Damasios focus on the biological scaffolding through which the body becomes present in and to the mind. They observe that “while the brain does represent, with fidelity, body states that are actually occurring, it can do far more than that: it can also modify the representation of an ongoing state, and most dramatically, it can simulate body states before they occur or body states that do not occur at all” (Damasio and Damasio 2006, p.16).

The authors demonstrate that, just as the body communicates its state to the brain, so the brain also communicates to the body. This loop implies that many of the body states that are being communicated to the brain by the body were derived from communication from the brain to the body in the first place. “Mental states cause brain states, which cause body states; body states are then mapped in the brain and incorporated into the ongoing mental states” (Damasio and Damasio 2006, p.17). Small changes in the brain can result in large changes in the body and vice versa. The information processing network referred to as the ‘body-loop’ (Damasio and Damasio 2006, p.18) functions to produce optimal controlling responses when the body provides the brain with information that correctly represents its current state. Additionally, the information processing network referred to as the ‘as-if-body-loop’ creates models of body states similar to those that would result if the body were to actually undergo predicted physiological or emotional responses. “In other words, the brain can simulate a certain body state as if it were occurring; and because our perception of any body state is rooted in the body maps of the somatosensing regions, we perceive the body state as actually occurring even if it is not” (Damasio and Damasio 2006, p.18). Mirror neurons, which were previously discussed in relation to empathy (see section 5.8), can even, for instance, simulate in the body an action or emotion that is not actually occurring.

11.9 Conclusion

It is reasonable to suggest that a lack of contact may result from a breakdown in the ‘as-if-body-loop’. This potentially offers an explanation for what the participants describe as a lack of “energy”. Part of what the participants describe as a lack of “energy” is a lack of contact with a proprioceptive sense of the capacity to do, the level of ‘physical energy’ that is available to the body. The participants also describe a pervasive sense that the ‘physical energy’ that is available

appears to be very limited and unpredictable. If CFS involves a general breakdown in contact, then this breakdown in contact would be as likely to affect contact with such a proprioceptive sense of the available ‘physical energy’ as with any other aspect of contact. Further, what the ‘as-if-body-loop’ implies is that such a breakdown with contact, passed from the brain to the body, in body state simulations, could lead to an actual breakdown of contact with either the proprioceptive sense of the level of ‘physical energy’ or, equally, could produce an actual low and unpredictable level of ‘physical energy’.

Processes that sanction action may be involved in how the brain simulates the ‘as-if-body-loop’, and also with what the brain does with the feedback derived from the ‘as-if-body-loop’. For instance, an organism may assess what resources are necessary for an action in order to create the ‘as-if-body-loop’ for that action. If the assessment of what is required is unreasonably high or the organism is making an unreasonably low assessment of the available resources then the organisms’ ability to create the ‘as-if-body-loop’ and the actual actions that they would predict would be impaired. The brain’s assessment of the resources that are required and the resources available for performance may be communicated by the brain to the body to create bodily reality and then communicated back to the brain by the body. Consequently, this could be a self sustaining phenomenon.

The Damasio’ final conclusion links the neurological and physiological scaffolding for the ‘as-if-body-loop’ to both the self and empathy for the other: “after allowing us to represent our own actions and emotional states, actual or simulated, they allow us to simulate the equivalent states of others. And because we have established a prior connection between our own body states and their significance, we can subsequently attribute the same significance to the states of others that we come to simulate. The body in mind helps us construct our selves and then allows us to understand others, which is nothing short of astounding” (Damasio and Damasio 2006, p.22). This potentially provides further explanation for the changes in self that are related in chapters 9 and 10. A lack of action means a decaying amount of proprioceptive information from which to make a self. In as far as transformation is an action, a lack of adequate contact could undermine the ability to transform. Perhaps the lack of letting go demonstrated by the ‘having an illness self’ is a reflection of a lack of contact. Similarly, a lack of emotional information may undermine the ability to accurately construct the self. All the activities that the participants describe as recharging their “energy” are described as meditative. Meditative, in this context, does not imply doing nothing. These meditative activities involve interoceptive (for example, insight meditation) and exteroceptive (for example, Qigong and Hatha Yoga) doing, including consciously choosing not to do. Is it possible that there is an

aspect of these activities that reinstates contact? Operational closure in the context of the Damasio’s work would certainly suggest that paying attention to emotion, which is both a phenomenal and physiological process, would produce neurophysiological changes.

12. Discussion and Conclusions

12.1 Introduction

The first four sections of this discussion reflect on the research. In section 12.2, I assess how enaction and first-person methods have contributed to the research and how this research may have extended or contributed to these research programmes. Section 12.3 considers the success of the method, given the processes of verification internal to the research. From this perspective, it is concluded that the method employed has been successful. This conclusion is subject to the constraint that the method has not been independently verified. General suggestions for future research on CFS are presented in Section 12.4.

Varela (1997) and Lutz (2002a) call for a mathematisation of phenomenology. The experience of conducting this research has highlighted the efficacy of this suggestion. The question is, how should this be achieved? Category theory is proposed in section 12.5 as a foundation for a mathematisation of phenomenology.

Towards the construction of a model which describes the process of the generation of meaningful and viable action, Boyd's OODA loop is reviewed in section 12.6. Connections between Boyd's existing model of action and autopoiesis, operational closure, and Gendlin's concept of felt meaning are drawn. In the next section, 12.7, a synthesis of concepts drawn from the enactive approach, Gendlin, and Boyd is used to develop a model for the process of the generation of meaningful and viable action. This model proposes a recursive loop involving felt meaning, contact, action, and perception. The action model proposed appears to be phenomenologically supported by the work of Gendlin and the findings of this research.

Given this new action model, a new interpretation of neurological findings in relation to CFS becomes possible. In section 12.8, a neurological phenomenon that correlates with the illness and involves a brain region that has a similar structure to the action model's recursive loop is identified in previous research results and compared with the action model and the results of this research. If the action model and the correspondence between the action model and this neurological finding bears out in further research, this correspondence may identify the brain regions involved in the illness process. Potentially this provides an objective diagnostic test for the condition and a point from which to investigate neurological and biomedical approaches to treatment. Phenomenologically based treatment suggestions are proposed in section 12.10. This section also mentions specific approaches to future research on CFS. A treatment approach to CFS will require an understanding of suffering. In section 12.9 it is suggested that the Prasangika definition of suffering is a suitable candidate for this task.

This discussion chapter is concluded in section 12.11.

12.2 Enaction and First-person Research

Thompson (2001) suggests a number of means by which the first-person phenomenological research programme may be extended. These include:

Clarification of the phenomenological method of investigating experience and exploration of its scope and limits in relation to cognitive science and contemplative practices.

Development of more refined taxonomies of empathy and value-sensing.

Consideration of the implications of this research for biomedicine (e.g., psycho-neuroimmunology), illness experience, and for empathy in the physician-patient relationship (Thompson 2001, p.29).

In this section, I assess how enaction and first-person methods have contributed to the research and how this research may have extended or contributed to these research programmes.

The main focus of the participants' discourse on CFS is the experience of the ability to act. Using an enactive approach in this research enabled an understanding of how the self emerges from the active handling of the objects of the world, even as those objects co-emerge or co-arise in this process of engagement with the world. An enactive approach allowed an exploration of how action underpins the participants' experiences of action, self, cognition, emotion and proprioception. Gallagher and Marcel's (1999) work provided the research with the necessary background to focus on the context of action in relation to access to the self, attention and intention. Gallagher and Marcel (1999) tend to focus on external context. The current research develops a focus on internal or interoceptive context. The research analysis suggests that, expressed through the directedness of action, intention with respect to attention was the most crucial aspect of the participants' interoceptive context to determining the possibilities for action they perceived to be available to them within the world.

Approaching the research through an enactive perspective allowed for a consideration of the full complexity of CFS as a psychosomatic illness in a manner that does not pathologise the necessary relationship between mind and body. By acknowledging the fact that human experience includes aspects of both the material and the mental without contradiction, I would argue that the enactive research programme offers one of the most comprehensive approaches to psychosomatic illness. Many other psychosomatic disorders could benefit from this approach. Considering the relationships of mutual constraint between the material and the mental provides a practically constructive and sophisticated approach to such relations. Although the present research is focused on the phenomenological aspects of the experience of CFS, by honouring a relationship of reciprocal constraint between these findings and neurophysiology in the conclusion of chapter 11, I point towards ways in which these phenomenal findings may inform

the neurophysiological aspects of the experience. The enactive approach allows recognition of the mind's own emergent processes. This is also pertinent to the consideration of psychosomatic phenomena.

The enactive approach makes clear how emergent global properties of the mind can affect local principles and how those local principles can give rise to mind. Further research into CFS could usefully investigate how, and whether, the local neurophysiological aspects of CFS, particularly at the onset of illness, have been affected by the mind and the environment and whether the mind's emergents, such as sanction, have affected these local principles. Conversely, clarifying how activities such as meditation can be used to influence both local states of the body and global states of mind and how changes in local states may influence the mind could be productive. In that sanction requires the subject to model another's cognitive and emotional processes, sanction and the evaluative processes that generate it involve empathy. Arguably, sanction needs to be included in the taxonomy of empathy.

The enactive approach has lent this research an understanding of the complex, embodied and psychosomatic nature of emotion. Enaction acknowledges that the embodied process of engaging with the world emerges out of the simultaneous and causally interdependent experience of emotion, cognition and somatic response. The analyses of self presented in chapters 1 and 10 suggest that an attention to the environment that leads to structural coupling that is not viable, such as what the participants perceive to be necessary for sanction to be achieved, and a lack of attention to emotion and proprioception accompany the experience of CFS and may cause a breakdown in cognition and enaction more generally. The same causal interdependence, between emotion, mind, body and world, allows the participants to utilise the action processes of 'meditation', 'surrender' and 'letting go' to progressively attain a more satisfactory level of functioning in recovery. Existential feelings (Ratcliffe 2005) are of fundamental importance to the participants' ability to somatically, cognitively and emotionally appraise and evaluate their experience of illness and recovery. By paying attention to each of these aspects of their experience, the participants are able to re-evaluate their relationship to action, including intention, and the relationship between self and the possibilities of being in the world. This analysis is informing with respect to the role of value-sensing in the experience of illness and recovery. The act of surrender narrated by the 'surrendering self' is very similar to Thompson's (Thompson 2005) value-sensing construct mode. Similarly, the focus of the 'recovered self' on "empathy" and "compassion" suggests construct mode value-sensing, whereas the exploration of "connection" related by the 'recovered self' is more akin to transcendent mode value-sensing.

The first-person method employed in this research does not reduce the research participant to an object. Instead, the participants were treated as subjects who actively participated in the process of knowledge creation. Participants were actively involved in the exploration and development of phenomenological invariants within the interview context. First-person research methods do not treat the phenomenological domain as a fixed corpus of knowledge but, rather, acknowledge the continual dynamic emergence of experience. The study of experience, therefore, is open to continuous refinement. This recognition facilitated the exploratory approach taken to the interviews, enabling the researcher to conduct the interviews in a systematic manner that was open to all aspects of the participants' experiences. Acknowledging the dynamic process by which experience and meaning emerge enables an interview process that is iterative and continually open to the refinement of experience. The research was able to incorporate singularity and variability as important components of an analysis of the intersubjective objectivity of the experience of CFS.

The emphasis that first-person methods place on incorporating empathy into the process of investigation was important for this research. As the second-person researcher, I was able to take the time to build rapport with the research participants. The 'know-how' that is available to bring to the research given my own life experiences (see chapter 7) contributed to my ability to function in empathic resonance with participants.

12.3 Reflecting on the Method

Recruiting participants that had recovered from CFS was of crucial importance to the success of this research. Where the phenomenological method is applied to the research of pathology this method would best also include the study of recovery and wellness. Results from the present research strongly indicate that doing so enabled a more accurate investigation of illness and a more comprehensive assessment of all the phenomenological structures of a given experience.

Recruiting participants from different geographical regions proved productive as this demonstrated how the different health care options available in these regions affected, or did not affect, the participants' experience of CFS more generally. Similarly, the analysis reveals how participants who had or had not been involved with ME Support Groups and general practitioners, particularly those practitioners who choose to specialise in treating the disorder, experience CFS differently. Without attending to these different subgroups, it would have been more difficult to achieve invariant saturation within the interview(s) with each participant and across the interviews as a whole and to determine that such saturation had been achieved.

As far as can be assessed without independent verification, the research analysis suggests that employing the Greimasian nomenclature as a formal tool provided an effective method for

investigating the structure of experience. Further research could extend and refine this technique for this purpose, building more bridges between it and, for instance, the aggregates, mental factors and wheel of karma.

Expressing semiotic invariant relationships in graph theoretical terms and using clustering proved productive in elucidating the web of relationships between large numbers of invariants. Other data mining techniques may prove similarly productive and this may be a road toward a formalised mathematisation of phenomenology. Further research may also explore the potential connections between the formal structure of invariant relationships expressed as graphs and dynamical systems models of the underlying cognitive processes. Cognitive processes need not suggest neural correlates but very likely correlate to dynamic patterns of neural activity whose dynamical invariants may at least structurally resemble (and indeed may actually be) the basic elements of cognitive and/or semiotic invariants.

The success of the cluster analysis in elucidating the web of relationships between the invariants was crucial to identifying the key structural elements of the experience of CFS. This significantly facilitated the analysis of the data.

Aspects of the experience of CFS are interrelated, some in complex ways. The cluster analysis employed here is an attempt to capture the relationships between processes. Rather than presenting a diagrammatic representation of the structure of the discrete components in the experience the cluster analysis aims to graph the structure of relationships between the node processes that constitute the CFS experience. These relationships are themselves processes. A focus on the relationships between and processes occurring within the structure of an experience will extend existing phenomenological research. Cluster analysis and category theory are potentially useful tools. Other data mining techniques may also prove efficacious.

12.4 General Suggestions for Future Research

Just as philosophers and scientists alike are examining the neurological basis of consciousness (Cosmelli et al. 2004; Cosmelli, Lachaux, and Thompson 2007, forthcoming; Metzinger 2000; Noë and Thompson 2004, 2004; Thompson and Varela 2001; Varela 1995; Varela et al. 2001), a number of theorists are examining various aspects of the neurology of action (Fournieret and Jeannerod 1998; Gallagher and Cole 1995; Georgieff and Jeannerod 1998; Haggard and Eimer 1999; Libet et al. 1983; Noë, Pessoa, and Thompson 2000; Praamstra et al. 1995; Prinz 1997; Berthoz 2000; Llinás 2001). This work demonstrates a developing understanding of the relationship between action, perception and agency. As Hurley concludes, “because a Two-Level Interdependence View sees perception and action as mutually and symmetrically interdependent, it frees us of the myth of the giving as well as the myth of the

given. It is not just expedient that perceivers are agents. But it is not just expedient that agents are perceivers, either” (1998, p.446).

The strongest support for paying attention to what the subject may be reflectively conscious of currently comes – paradoxically – from the neurosciences. Because as neurological data have become increasingly precise, the question has arisen as to how they can be given a semantic, and how can they be clearly linked to subjective experience. And how could this be done other than by the expression of the subject himself, which can only be based on an introspective act. (Vermersch 2009, p.26)

This call from neurology is powerful evidence for the need to combine first-person data with third-person processes. I would argue that neurology is not the only science from which this paradigm shift will be motivated. Unfolding more fully the potential of this research programme will require realising methodologies and methods that allow for differing time scales. Neurological research may best demonstrate the power of the circulation between first and third-person on the time scales corresponding to that concerning minimally separable perceptual events and single moments of consciousness. What is also required is a robust approach to narrative time scales. These time-scales are not distinct and will reciprocally inform each other.

The analysis presented in this research suggests that a necessary next step for a neurophenomenological approach to CFS would be to investigate the neurology of action and how this neurology may be affected by perception and agency in sufferers of CFS. More generally, this research suggests that investigating the neurology and physiology of contact could be fruitful. Further, the question of how the neurology and physiology of contact may be affected by action, perception and agency needs to be investigated.

Several authors are investigating the neurodynamics of consciousness, conscious experience, perception and the self (Le Van Quyen and Petitmiengin 2002; Lutz et al. 2002b; Lutz and Thompson 2003; Cosmelli et al. 2002; Tani 1999; Thompson and Varela 2001; Cosmelli, Lachaux, and Thompson 2007, forthcoming). The present research suggests that it would be valuable to investigate the neurodynamics of action and contact, particularly with respect to the self in CFS and in the meditative states that the recovered participants describe. Investigating the neurodynamics of action in meditation more generally may also be revealing.

O'Regan, Myin, and Noë (2005) develop an account of the phenomenal feel of perception based on two key features: corporality and alerting capacity.

‘Corporality’ refers to the way that changes in our bodily movements (even tiny ones) radically affect our sensory inputs – for instance, when looking at a cloud, by moving my head left, the cloud ‘moves’ from the centre to the right-hand periphery of my visual field. ‘Alerting capacity’ refers to a (complementary?) property, whereby a change in sensory input will elicit a motor response so as to orient attention towards the change – so that a large bird flying across the cloud will make me shift my gaze rightward, bringing the cloud back into the centre of the field. (Torrance 2005 p.362)

According to O'Regan, Myin, and Noë (2005), these properties of sensory phenomenality are measurable. Corporality and alerting capacity may provide useful conceptual tools for further research concerning the nature of 'what it is to experience CFS'.

This research employs Torrance's second enactive approach. Recent developments in the field are working towards a third enactive approach coined social enactivism (Di Paolo 2009; McGann and De Jaegher 2009; Stawarska 2006, 2006; Steiner and Stewart 2009). Social enactivism stands to be useful for future research on CFS.

12.5 Category Theory as a Potential Approach to the Mathematisation of phenomenology

Varela (1997) and Lutz (2002a) call for a mathematisation of phenomenology. Kauffman's (2002) research moves in this direction. How this would be achieved, however, was beyond the scope of this early work. The project of mathematising phenomenology will remain open to criticisms such as that of Brown (2008) until a mathematical and epistemological approach that is showing practical and theoretical promise is established.

Yoshimi (2007) calls for an integration of phenomenology and cognitive science and acknowledges that this will require a mathematised phenomenology.

I believe that a dynamical approach to Husserlian phenomenology holds out considerable promise for integrating phenomenology and cognitive science. ... Drawing the parallels properly will require a suitably mathematized phenomenology. (Yoshimi 2007, p. 290)

In contrast to Brown (2008), Yoshimi also demonstrates that mathematising phenomenology is not an incoherent project given the capabilities of modern mathematics, but Yoshimi also does not suggest how this may be achieved.

The neurophenomenological program aims, in part, to relate neurological behaviour to phenomenal data and the structure of experience in mutual constraint (Varela 1997). The challenge neurophenomenology faces is that these realms of knowing are disjoint. Neurological data, phenomenal data and semiotic systems are separate mathematical universes, in that these data are of incommensurate and incomparable kinds. Mathematics, however, provides a tool for working with objects of different kinds that nevertheless exist in and/or behave in mutually constrained relationships: category theory.

A mathematical category consists of a collection of objects, a set of morphisms that map objects to objects, an identity morphism that maps each object onto itself, and the (associative) operation of composing morphisms¹¹³. Category theory provides a way to proceed from categories and constraints on morphisms to a fully developed mathematics of the categories.

¹¹³ For a formal definition of a category I refer the reader to Appendix B of Goguen (1999).

Category theory builds upwards from the structure of connections between categories to the necessary implications of those connections for the algebras of those categories. Once algebras and the nature of the objects of the categories can be identified one can then also show how to connect the dynamical structures of each category in mutual constraint. In effect, this is the co-dependent arising of structure in and between distinct categories.

Decock (2006) argues that because there is evidence to suspect that phenomenal data cannot be represented in a metric space this implies that there is no phenomenal space. It is possible, instead, that phenomenal spaces exist but are non-metric. It is also possible that a correct mathematical representation of phenomenal data would not be contained in a space but rather in some other mathematical object. Category theory may provide the tools to resolve the nature of a representation of phenomenal data that is consistent with and grounded in phenomenology. The key here would be the grounding of the representation in phenomenology rather than a priori assumptions.

In order to mathematise phenomenology it may be necessary to mathematise neurophenomenology. In mathematising neurophenomenology, the categories involved will include the entire array of the disciplined approaches to human experience and their tools and “the entire array of scientific correlates which are relevant in cognitive science” (Varela 1996, p.330). It seems likely that no one of these categories will manifest enough constraints to specify a structure for a mathematised neurophenomenology, however, in combination they are likely to provide sufficient constraints. This implies that mathematising phenomenology alone may be impossible. This could be considered analogous to establishing the shape of a tent where phenomenology, disciplined approaches to human experience, and the scientific correlates which are relevant in cognitive science each contribute guy ropes. Without enough guy ropes specified the dimensions of the tent cannot be realised.

Some of the necessary categories for the mathematisation of phenomenology are relatively straightforward because their formalisations are already well understood. The applications of mathematics to neurology have been extensively studied, for example. There is also a significant literature on algebraic semiotics founded by Goguen’s (1999) category-theoretical discussion of algebraic semiotics.

What is needed is a mathematised phenomenology and mathematised phenomenological research process. Toward this end, basic element analysis proposes a subject, object, relation tuple as the basic structural element of experience. The collection of all possible such basic elements together with such observational constraints as the mental factors, and others, could be

formalised into a mathematical category, subjects and objects being the objects of the category and the relations being its morphisms (McGregor 2010).

Introspection (Vermersch 1999; Vermersch 2009) potentially provides detailed access to first-person experience. To explore this in a rigorous manner, two components are necessary. Firstly, an understanding of symbolisation and the way symbolisations derive their meaning from experience in the first person. Gendlin (1962) has provided a description of how meaning arises from the relation between experience and symbolisation, which could generate the basis of a formalisation of the symbolisation of experience. Secondly, rigorous intersubjective processes for gathering phenomenal data that produce authentic and consistent symbolised results are necessary. The explication interview technique described by Vermersch (1999; 2009) and Maurel (2009) acts as a starting point and is also similar to methods employed in this research. Similar processes for intersubjective validation have been described by Petitmiengin-Peugeot (1999) in her study of intuition and Petitmiengin and Bitbol's (2009) work on the validation of first-person interview data.

Finally, what will be required is a means for discovering structure in symbolised first-person data. The semiotics of Greimas and Courtés (1979), as used in this research for example, provides a potentially useful formalisation and nomenclature of practical analytic techniques for systems of symbols such as first-person reports. In providing a theory of algebraic semiotics Goguen (1999) demonstrates how semiotics can be expressed in terms of category theory. For example, there is a very strong connection between commutative diagrams in category theory and the semiotic square of Greimas and Courtés (1979). In this research the application of Greimasian semiotics to a large symbol system (resulting from coded interview data) and the use of graph theory and clustering in doing so is a simple practical example of the benefit of mathematising phenomenological research. In future research, there are a large number of natural language processing techniques from computer science that stand to save much of the labour requirement of a manual process; for examples, see Tagarelli (2008) and Huang et al (2008).

At each step in the process of constructing a mathematised phenomenology, category theory and abstract algebra could be utilised to provide a full mathematical formalisation of phenomenology. Graph theory and linear algebra could provide analysis tools for the structures that arise both during the mathematical formalisation of phenomenology and those structures that arise from the application of the mathematised phenomenology to phenomenological data. The category-theoretic ability to integrate constraints from each level of re-representation of experience is what could give this approach its power.

A fully mathematised phenomenology could potentially demonstrate the mechanisms of action in precise mathematical terms such that they could be directly compared to neurological data, modelled in digital form, and perhaps even executed in software.

12.6 Boyd's OODA Loop as a Model of the Action Process

Military theorist John Boyd developed a general theory of the dynamics and process of functional human action in both the individual and organisational context (Boyd 1976, 1979, 2005, 2006; Boyd 1991; Richards 2004). Boyd's application for this theory was to facilitate the disruption of adversaries' ability to act in military contexts and allow allies to resist such disruption. Boyd's theory has given rise to broader applications, especially in business (Adolph 2006; Richards 2004).

In a presentation Boyd states:

As human beings we cannot exist without an external or surrounding environment from which we can draw sustenance, nourishment, or support... Interaction permits vitality and growth while isolation leads to decay and disintegration. (Boyd 2006 p.29)

This statement concurs with Varela, Thompson, and Rosch's (1991) concept of operational closure in the sense that, although an organism has operational closure, it is a matter of survival that the organism's actions fit the environment with sufficient accuracy. Similarly, Boyd states "the actions we take as individuals are closely related to survival, more importantly, survival on our own terms (Boyd 1976)".

Boyd gives a schematic representation of the process of appropriate action, called the OODA loop after its principal processes of Observation, Orientation, Decision and Action. Boyd defines orientation as follows:

Orientation is an interactive process of many-sided implicit cross-referencing projections, empathies, correlations, and rejections that is shaped by and shapes the interplay of genetic heritage, cultural tradition, previous experiences, and unfolding circumstances. (Boyd 2005 p.15)

Orientation, seen as a result, represents images, views, or impressions of the world shaped by genetic heritage, cultural tradition, previous experiences, and unfolding circumstances. (Boyd 2005 p.13)

Boyd does not give a precise definition of observation, decision or action, however his use of these terms implies that orientation and decision taken together can be regarded as equivalent to a statement of operational closure, while observation and action encapsulate interactions with the environment. This implies that the OODA loop is an autopoietic process (Maturana and Varela 1980; Varela 1979; Weber and Varela 2002), and it is also an adaptive process (Di Paolo 2005).

These autopoietic processes Gendlin (2000) points out are both conscious and unconsciously emerging from the body.

The full complexity of the process of orientation encompasses, at least, elements of autopoiesis, contact, intention, empathy, intersubjectivity, and enculturation. Gendlin describes in phenomenological terms how orientation occurs through felt meaning, although he does not use the term:

The dependencies of the intellect on culture, periods of history, biological or psychological needs, choices of methods and principles, are not cases of questionable intellectual processes. All these factors that influence the intellect do so through optimal, normal functions of felt meaning and can thus be examined in the light of these functions. (Gendlin 1962 p.224)

Adolph highlights the importance of orientation to the OODA loop:

The OODA loop is most definitely not a linear staged decision making model and while it is colloquially referred to as a loop; it is a misnomer to think of it as a single loop. Observation, orientation, and action occur continuously and simultaneously. Orientation becomes the most important part of the OODA loop because it shapes the way we observe, the way we decide, and the way we act. (Adolph 2006)

The OODA loop strongly parallels the omnipresent mental factors in the sense that, although the division into separate facets is quite different, the representation of how action functions that the OODA loop process offers is equivalent to the sum of the omnipresent mental factors, those aspects that are always present in experience (Varela, Thompson, and Rosch 1991, p.68). This suggests that all actions share a unique process that is omnipresent in experience and that the OODA loop is a candidate generic dynamic process model for self-sustaining cognition and action. This may further suggest that experiential consciousness is necessary for the adaptivity of action.

Boyd's notion of a 'dialectic engine' (Boyd 1976) of destruction and creation of conceptual structure is, firstly, very strongly aligned with the notion of autopoiesis, and, secondly, is described in terms that align with the mathematisation of phenomenology. Boyd uses an analogy to entropy and the second law of thermodynamics, an analogy that has been widely used as an optimisation strategy in mathematics under the name of simulated annealing. One could see the OODA loop as a continual process of adaptive simulated annealing optimising the match of the individual to a contingent local optimum point on a surface of conceptual viability embedded in some phenomenological manifold (McGregor 2010).

The omnipresent mental factor of contact involves both contact with the external senses and contact with consciousness. Contact with consciousness is an essential component of orientation, since 'images, views, or impressions' can only be found in consciousness, the "dualistic sense of experience in which there is an experiencer, an object experienced, and a

relation (or relations) binding them together” (Varela, Thompson, and Rosch 1991, p.67). Boyd’s use of the term observation implies that contact with the external senses is contained within observation in the OODA loop. Thus the OODA loop gives us a model for the contribution of contact to action: contact is an essential part of observation and orientation, and thus leads to all decisions.

By Boyd’s definition, the process of orientation includes the factors of enculturation. The process of orientation, in this model, is the means by which all the aspects of enculturation are incorporated into an individual’s process of action and as such potentially provides a model of the mechanism for enculturation and its consequences.

Boyd’s work is both constructive and destructive. From a constructive perspective, Boyd’s OODA loop provides a model that explores the dynamics of functional action. Also from a constructive perspective, Boyd describes how the OODA loop can be made robust in the face of disruption. From a destructive perspective, Boyd identifies how the OODA loop can be disrupted, in other words, how the process of action can be made to fail. Boyd observes:

In order to win, we should operate at a faster tempo or rhythm than our adversaries - or, better yet, get inside [the] adversary’s Observation-Orientation-Decision-Action time cycle or loop. ... Such activity will make us appear ambiguous (unpredictable) thereby generate confusion and disorder among our adversaries - since our adversaries will be unable to generate mental images or pictures that agree with the menacing as well as faster transient rhythm or patterns they are competing against. (Boyd 1979)

Here Boyd suggests two mechanisms for the failure of functional action. Firstly the observation of inaccurate information and secondly information that arrives too quickly to be processed or, ideally for Boyd’s application, both. Further, Boyd observes the consequences of the failure of functional action:

The ability to operate at a faster tempo or rhythm than an adversary enables one to fold [an] adversary back inside himself so that he can neither appreciate nor keep-up with what’s going on. He will become disoriented or confused; which suggests that unless such menacing pressure is relieved, [the] adversary will experience various combinations of uncertainty, doubt, confusion, self-deception, indecision, fear, panic, discouragement, despair, [*et cetera*], which will further disorient or twist his mental images/impressions of what’s happening; thereby disrupt his mental/physical maneuvers for dealing with such a menace; thereby overload his mental/physical capacity to adapt or endure; thereby collapse his ability to carry on. (Boyd 2006)

By the phrase “fold [an] adversary back inside himself” Boyd is describing a state whereby the observer’s perceived options for action have been minimised; their space of possible action has been folded into a limited and predictable volume. Boyd suggests that once orientation is lost, confusion will cause further disorientation, to the point of the collapse of functional action. Considered in enactive terms, while disruptive external input is maintained, operationally closed

dynamics feed the confusion back on itself, and the organism remains in a self sustaining disrupted state in which functional action is no longer possible. In terms of dynamical systems theory, Boyd has described how the available regions of state space have been reduced dramatically, to the point where the organism is trapped in a dynamic decompensation.

Actions are one form of symbol. In the OODA loop, there are two forms of action, firstly, observation of self and other, and, secondly, individuals actions in relation to both self and other. Given Boyd's original formulation of the OODA loop in the context of aircraft combat, these are inherently intersubjective actions. The orientation stage of the OODA loop is a mechanism for processing experience. This implies that the OODA loop is an intersubjective model for the creation of meaning in the symbolisation of experience, in the case where the symbols are actions.

12.7 A Model for the Generation of Meaningful and Viable Action and the Role of Contact

The following table presents some striking equivalences and similarities between the concepts and terms found in the enactive approach, and the work of Gendlin (Gendlin 1962) and Boyd (Boyd 1976, 1979, 2005, 2006; Richards 2004). Each of these projects speaks to the nature of cognition, action and contact. A synthesis of these works is presented here with the intention of providing insight into the nature of contact and its role in consciousness, cognition and action. To achieve this end a model of action is developed and the critical role of contact within this model is identified. This model could be considered a systems architecture for emergence.

Boyd: OODA loop		Gendlin: On Meaning		Enactive Approach
Observation	=	Observation	≈	Aggregates 1-4
Orientation	=	Orientation Resonating	≈	Intention, Attention, Discernment, Feeling, Contact
Decision	=	Felt sense of decision, Receiving	=	Intention Letting Come
Action	=	Action	=	Embodied Action
OODA Loop	=	Cognition	=	Cognition as Embodied Action
		Contact	=	Contact
		Felt Meaning	=	Consciousness All 5 Aggregates
		Pre-reflexive	≈	Grasping, Craving

Initially the equivalences between these systems with respect to observation, orientation, decision and action will be outlined. All three approaches are theories of the production of viable, sustainable and meaningful action.

Boyd does not provide a definition of observation, however, his use of this term is entirely consistent with Gendlin's. For Gendlin the purpose of observation is to bring forth felt meaning. He states: "like thought, observation involves felt meanings. Some thing observed is always observed as *meaningful* (Gendlin 1962 p.67)". The role of felt meaning in the generation of observation applies to both observations that we symbolise in expression and those which remain prereflexive: "we conclude that felt meanings constitute the meanings of observation that we don't make explicit, and that they play a necessary role also in the observation we do explicate (Gendlin 1962 p.68)". Observation is any action that creates perception, an observation which is fundamental to the enactive approach: "in a nutshell, the enactive approach consists of two points: (1) perception consists in perceptually guided action and (2) cognitive structures emerge from the recurrent sensorimotor patterns that enable action to be perceptually guided (Varela, Thompson, and Rosch 1991 p.173)". Felt meaning is just such a cognitive structure, and Boyd's (1976) notion of a 'dialectic engine' is clearly his process for the emergence of cognitive structure.

As previously discussed (see section 12.6), for Boyd, orientation is the central and most influential process in the creation of action: "orientation, seen as a result, represents images, views, or impressions of the world shaped by genetic heritage, cultural tradition, previous experiences, and unfolding circumstances (Boyd 2005 p.13)". For Gendlin, felt meaning is the basis of orientation: "we orient ourselves in situations and make appropriate responses, all on the basis of the felt meanings of observation (Gendlin 1962 p.68)". Gendlin identifies the role of the prereflexive, in parallel with symbolic meaning, in the orientation of goal directed problem solving and the creation of cognitive structure: "... the experienced process of problem solving involves specific functions of felt meaning. It is not only the ever-present experienced side of all symbolic meaning, but felt meaning also functions vitally without symbols in the process of obtaining adequate symbols of new ideas (Gendlin 1962 p.75)". This implies that felt meanings created in the process of orientation, or problem solving, guide the 'adequate symbols of new ideas', including those symbols that are the actions which result. Gendlin's process of resonating is orientation in practice:

Resonating: Go back and forth between the felt sense and the word (phrase, or image). Check how they resonate with each other. See if there is a little bodily signal that lets you know there is a fit. To do it, you have to have the felt sense there again, as well as the word. (Gendlin 1978 p.44)

This is a critical act or movement in Gendlin's therapeutic focusing technique. To an extent the focusing technique is about improving the process of orientation. The enactive approach uses the term intentional attitude for the results of the orientation process.

The intentional attitude of a person consists of the content of their current purposive intentions which is itself a function of their attentional focus. It is inferred from the performance of perceptual, motor and linguistic activities, from phenomenological report, and also from the task demands and external situation. The total context of an action is made up of the intentional attitude and the external context, which we see as largely but not totally interdependent (Gallagher and Marcel 1999, p. 276).

Intentional attitude encapsulates the influence of orientation on resulting actions. Intentional attitude is composed of the five omnipresent mental factors, including attention, discernment, feeling, contact and intention.

Boyd's work originates from contexts in which decision is vitally important, there is frequently a delay between the decision to act and the correct moment for action, and where action must frequently be prepared in advance. Consequently Boyd separates decision from action, and incorporates the necessity to prepare multiple decisions for sequences of action that must be executed with precise timing. Boyd's model was also intended to represent the dynamics of organisations where decisions must be followed by communication in order to organise action. This separation of decision from action is encapsulated in the enactive approach by the mental factor of intention, which precedes action. Gendlin does not separate decision from action. Gendlin does, however, identify the felt sense of a decision and intended action arising: "golfers aim with the feel of the whole body ... golfers cannot describe that feeling of 'ready', because too many details are involved. They know the feeling when it comes, however. When the body-feel is right, they swing" (Gendlin 1978 p.84). The sixth movement in the focusing technique, receiving, provides a space in which such a felt sense towards decision and action may arise and be brought forth into reflexive consciousness. Receiving is remarkably similar to letting come, a gesture within epoche (Depraz, Varela, and Vermersch 2003 p.24).

In all three approaches, action itself is largely defined in terms of its causes and consequences. With respect to action Gendlin shows how the felt meaning of the decision to act prefigures the experience of the action itself: "considered as something observed from the outside, an action is like any other observation. From the phenomenological viewpoint of the agent, an action has felt meaning even before he can observe it externally (Gendlin 1962 p.68)". This felt meaning is bodily in source. This is true also of speech: "in speech, as in all action, there is both external observation and the felt sense of what is intended (Gendlin 1962 p.69)". From the enactive perspective cognition is embodied action (see section 4.14) and, as such, action is explicitly considered to be a response to all the constraints on the organism. The

embodiment of action is implicit in Boyd's OODA loop whereby orientation is considered to include any and all influences on the resulting actions taken, including such explicitly embodied influences as genetics and skill training.

Having identified the correspondences for each of the components of the OODA loop it is now necessary to consider the parallels between each of these approaches to the generation of meaningful, viable and sustainable action. In the enactive approach, minds and cognitive processes are the means by which an organism preserves itself in its environment: "mind arises from the completely embodied process of actively coping with the world (Varela 1999a, p.72)". For Boyd, the OODA loop is literally a matter of 'survival on our own terms', both as an individual and for organisations or societies. The OODA loop is Boyd's entire process of generating viable and meaningful action. Gendlin does not focus directly on the viability of actions, however, he is concerned with their meaningful nature. For Gendlin cognition is the global process for the generation of meaning. Meaningful action, intellect and felt meaning are aspects of cognition. For Gendlin, intellect is the process that brings forth actions and symbols from felt meaning.

Contact plays a crucial role in all of these approaches to the production of meaningful, viable action. Gendlin claims:

This study has presented several functional relationships in which, with the aid of symbols, experience can function meaningfully. We have answered the question regarding experience as a source of meaning by showing that felt meaning functions to make symbolized meaning possible. But how is experience – other than felt meaning – a source of meaning? In other words, how is sense perception, external observation ... a source of meaning? The answer is the same: whatever is a source of meaning is so to us through the medium of felt meaning (Gendlin 1962 pp.219-20).

What Gendlin here establishes is the means by which any form of perception, observation or symbol derives its meaning, that is, from experience calling forth felt meaning. In effect this is a description equivalent to the statement that the fifth aggregate, consciousness, contains all the previous aggregates and is omnipresent in all experiences. Moreover, experience by way of felt meaning is the source of all meaning and, therefore, of all meaningful action.

Gendlin states:

One can say that intellect is in *direct* contact (in functional relationships of mutual dependence) only with felt meaning. This terminology distinguishes purely conceptual apparatus – called intellect – from felt experiencing. Or one can say that felt meaning is a stage in cognition. This terminology includes both felt meaning and the conceptual apparatus in one process of "cognition" and thus focuses on felt meaning as an early, preconceptual stage of cognition (Gendlin 1962 p.220).

Gendlin here articulates the relationship of the intellect to felt meaning as one of direct contact and mutual dependence, or, in other terms, co-dependent arising. Further, the intellect is *only* in

contact with felt meaning even where this is the felt meaning of the intellect itself. The intellect arises from and is mutually dependent with felt meaning. Intellect here is referred to as a ‘purely conceptual apparatus’ that constitutes a process of cognition. However, this conceptual apparatus of cognition is based on felt meaning and therefore felt meaning can be considered to be the preconceptual or pre-reflective foundations from which intellect as an aspect of cognition is generated: “From this study it follows (a) that intellect is not in direct contact with perception or reality, however defined; (b) that intellect always optimally depends upon the functions of felt meaning (Gendlin 1962 p.221)”. Felt meaning is thus equivalent to the enactive concept of consciousness, the fifth aggregate. Further, contact is the process by which intellect depends on the functions of felt meaning, which echoes its definition as an omnipresent mental factor within consciousness in the enactive approach, bearing in mind that felt meaning, senses and objects include purely internal cognitive structures: “as a cause, contact is the coming together of three distinct items—a sense, an object, and the potential for awareness (Varela, Thompson, and Rosch 1991 p.119)”. For the Damasio’s ‘as-if-body-loop’ (Damasio and Damasio 2006, p.18), contact would be established between the object sensorimotor planning, the sense of proprioception, and the potential for awareness of possible future action.

Felt meaning is a stage in cognition. In Gendlin’s terms, the entire pathway of cognition, passing from felt meaning, through contact, the intellect, one of the actions—action, symbolising or observation—and returning to the felt meaning of the results of these actions, is a description of how cognitive structures emerge to create action.

Each process of Boyd’s OODA loop can be identified in this pathway of cognition. Orientation occurs between felt meaning and the intellect, the intellect creates decisions that lead to action and observation, and these lead back to orientation. Given that felt meaning connects to the intellect by way of contact, then this implies that contact is central to orientation. Since every path of this cognitive pathway eventually leads back to felt meaning, including those that create externally observable actions, this model of cognition has operational closure. Or, in Gendlin’s words: “The function of felt meaning is therefore a necessary medium between intellect (conceptual apparatus) and whatever else it is in relation with (Gendlin 1962 p.221)”.

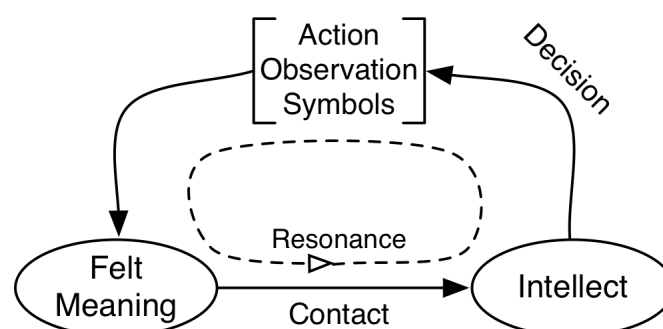


Figure 15: Schematic representation of the recursive pathway of production of action from experience

By drawing the parallels discussed in this section it becomes possible to create a representative model of the production of meaningful and viable action in context. Displayed schematically in Figure 15, this model is a recursive loop, from experience as conscious felt meaning, through contact, to the intellect (both pre-reflexive and reflexively symbolised through resonance with symbols) to produce actions. Actions are observed to produce an experienced felt meaning, and therefore the loop is operationally closed.

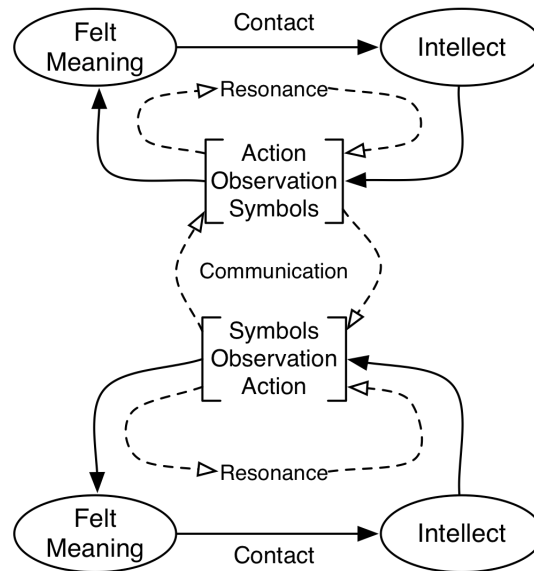


Figure 16: Intersubjective action model

In this model some actions are intended to elicit experience through observation (perhaps observation of other individuals). Some actions are explicitly symbolic (some of which are intended to be communicative to others, as shown in Figure 16). Some actions are straightforwardly directed toward survival. Other actions, whether observational, symbolic or operational are purely internal operations on the state of the organism and may have no externally visible result. Observational actions on the state of the organism are the reflective gestures of phenomenology and psychotherapy. Symbolic actions on the state of the organism are the internal streams of consciousness, and include decisions, resonating exploration of felt meaning, and internal dialogue. Operational actions on the state of the organism are simply thoughts, especially of the pre-reflexive, embodied, knowing-how or emotional kinds. Since some actions and some observations are directed toward interaction with others, this is a psychosocial enactive model. In semiotic terminology, in the case where an action is a continuous process, the action loop takes the form of the continuous initiation, competence, performance and monitoring of the action performed in parallel, where monitoring refers to the sanction and evaluation process.

The model of the action production loop clearly critically depends on contact. This implies that any disruption of contact or reduction in the intensity of contact will have consequences for the meaning of action, and in extreme cases even the viability of action. Selective disruptions of contact would have selective effects on action, and these may be subtle and complex due to the recursive re-injection of felt meaning into the loop. Further, since all action is meaningful, one can conclude that there is a possibility of phenomenologically observing, symbolising and drawing conclusions from the specific character of disrupted action, and that these conclusions will shed light on disruptions of contact. Since felt meaning is even necessary for pre-reflexive cognition, *any* cognitive faculty can be disrupted by a disruption of contact.

Fundamental theses of Gendlin's work include firstly, that felt meaning (experiencing) is omnipresent, regardless of the extent to which it can be consciously accessed, articulated or conceptualised and, secondly, that felt-meaning is a necessary functional component of cognition: both reflective and pre-reflective (Gendlin 1962: Chapter II). Further, Gendlin observes:

Nothing is as debilitating as a confused or distant functioning of experiencing. And the chief malaise of our society is perhaps that it allows so little pause and gives so little specifying response and interpersonal communion to our experiencing, so that we must much of the time pretend that we are only what we seem externally, and that our meanings are only the objective references and the logical meanings of our words (Gendlin 1962 pp.15-6).

Gendlin's words could be considered a description of contact found to be lacking and an observation of the cultural context in which such a lack of contact might arise and be perpetuated. Gendlin here describes a mild but pervasive form of the same process of disorientation that Boyd takes to the point of complete failure in action.

In contrast to most discussions of these problems, we do not assume that the intellect ought optimally to be direct, untrammelled contact with its object. Therefore we do not see the influence of culture or psychological need or methods as principles as unusual. Intellect is always subject to the role of felt meaning, and thus indirectly to anything that affects felt meaning. Conversely, if these factors influence intellect, they can do so only through the medium of felt meaning (Gendlin 1962 pp.221-2).

It is necessary to have existed within some cultural setting in order to have a set of symbols and the symbolising skills with which to communicate experience. Gendlin's work explores the functional relationships between experience, meaning and symbols as co-arising. It is necessary to have inherited through enculturation the symbols required to have certain experiences just as much as it is necessary to have experiences in order to bring forth any symbols. For example, it is necessary to learn to read music in order to have the experience of sight reading a score, just as much as you must have heard or imagined music in order to be able to write a score.

An individual's enculturation provides them with a set of schemes out of which to create their own meanings.

It is from the logical forms that logical implications follow! It is when the logical forms are imposed on (employed in symbolizing, selecting, differentiating) experience that certain differentiations in experience can be made. (Gendlin 1962 p.218)

Gendlin's statement points out that logical form, symbol, and enculturated inheritance are direct mechanisms in the creation experience. This implies that it is possible to train people to have specific experiences, a fact which has important therapeutic application.

Gendlin provides a detailed analysis of the functional and epistemological implications of the non-arbitrary relativity of symbols in their functional relationship with felt-meaning (Gendlin 1962: Chapter VI). He makes clear that all terms within a scheme are relative to the scheme in which they function. Terms derive their meaning from felt meaning and their relationship to other terms within the scheme. Equally schemes can have functional equality such that certain terms with one scheme are functionally equivalent to terms in another scheme. Consequently it is possible to build bridges between such terms and schemes. The research participants' discourse on CFS is the scheme through which they articulate their experience of CFS. In Chapter 11 I propose that the manner in which the term 'energy' functions within this scheme is equivalent to both Gendlin's and the Buddhist concept of 'contact'.

If this equivalence is the case, then the consequences of the disruption of contact identified above would follow, specifically an inability to create meaningful or even viable action. This is precisely what was concluded in my analysis.

It is plausible to suggest that this state and the "grief" reported by the contemporaneous 'having an illness self' are in fact not so much expressions of emotion as descriptions of a cognitive absence, a state whereby cognitive actions that may have at some point previously existed have largely ceased to occur. (This thesis, see section 9.9.4)

Although the 'having an illness self' is trying to act, these actions are not experienced as reliably efficacious. This undermines action, the self and, in its ambiguity of neither ill nor healthy, the ability of the 'having an illness self' to bring a sense of self to action. It is a potentially permanent state of being that cannot act and cannot not act. (This thesis, see section 9.9.4)

By contrast, the recovered interviewees describe a rapid return of viable and meaningful action.

I10: I was in charge of my life and no one was going to, no one would convince me that this was a stupid thing to be doing or anything else ... That's how totally determined I was and how totally I owned my life all of a sudden. Probably for the first time in my life, I felt in charge of my life, totally. And, you see, the psychological shift for me in that was absolutely amazing because it's always what I'd wanted ... Yes. From powerlessness to power, more than ever. It wasn't just back to how I'd been but way beyond, that sense of autonomy, of total autonomy in my life. And that happened quite quickly.

It would suggest that the CFS illness state represents a state of dynamical decompensation. I have proposed that in the action loop, contact with the senses is essential to observation and contact with consciousness is essential to orientation. My analysis of the interviews suggests that CFS involves a general breakdown of contact, both with the senses and with consciousness. On this basis, if in CFS it is the case that contact is disrupted, then observation and orientation will both be disrupted. This would disrupt the action loop sufficiently to cause the type of dynamically decompensated state described above. In other words, a failure of the action loop can be caused either by becoming overwhelmed by events or by a breakdown of contact, with similar results, because in both cases information arrives faster than the rate at which the organism's action loop can process it.

Boyd's advice to combatants for prevailing in a conflictual situation is to operate at a faster tempo than an adversary in order to cause confusion. In the case of CFS, I suggest that a partial loss of contact with consciousness decreases the sufferer's acuity of observation and effectively slows their action loop to below the rate at which they can maintain a match with their situation; effectively then, the world is operating at a faster tempo than the sufferer, and the same type of decompensation occurs.

In his discussion of the development of the concept of autopoiesis within the enactive approach Torrance (2005) comments:

Autopoiesis has been defined in various ways: Thompson (this volume) characterizes an autopoietic system as one whose component processes must "recursively depend on each other for their generation and their realization as a system," so that they "constitute the system as a unity, also defines (enacts) its environment as a domain of meaning, and defines things in its environment as meaningful within that domain (in the way that, for instance, sugar is meaningful for bacteria). Could it be, then, that what is missing in the rather focused enactive account of perception proposed by O'Regan et al. is a more widely enactive concept of the perceiver as an autonomous, or autopoietic, self-maintaining individual? This certainly seems to be Thompson's view, and it would be one way to unify the two strands of enactivism mentioned earlier.

The model of action developed in this section may be a candidate for Torrance's "more widely enactive concept of the perceiver as an autonomous, or autopoietic, self-maintaining individual", that is to say, an individual who continuously observes or perceives the felt meaning of their actions.

12.8 The Neurological Correlates of CFS and the Action Model

One possible approach to testing the proposal that contact is disrupted in CFS is to investigate the functioning of CFS sufferers' senses, particularly those around kinaesthesia. As discussed in section 2.4, Wallman, Morton et al. (2004) have investigated CFS sufferers' perceived effort in exercise situations, and found that CFS sufferers do rate their effort levels for a given exercise

result significantly higher than matched controls (Wallman et al. 2004). Further, Sherlin, Budzynsky et al. (2007) tentatively identify a brain region that they propose is involved in the management of energy (Sherlin et al. 2007, p.1438). This region lies within a part of the brain that other studies of CFS sufferers have shown demonstrates significant perfusion and metabolic abnormalities (Abu-Judeh et al. 1998; Basted, Saunders, and Logan 2001; Costa, Tannock, and Brostoff 1995; de-Lange et al. 2005; Khan et al. 2003; Natelson et al. 2005; Palaniappan and Sirimanna 2002; Siessmeier et al. 2003; Tirelli et al. 1998; Yoshiuchi, Farkas, and Natelson 2006).

Sherlin, Budzynsky et al. (2007) have investigated characteristic patterns of neural activity in the brains of CFS patients and their healthy identical twins. The authors find significant differences in brain activity in the limbic system, which includes the brain stem and specifically the thalamus. Tirelli et al. (1998) also report: “the most relevant result of our study is the brain stem hypometabolism which, as already reported in a perfusion SPECT study, seems to be [a] marker for the *in vivo* diagnosis of CFS.” (Tirelli et al. 1998). Hypometabolism in the thalamus and brainstem could be either cause or consequence of CFS.

Llinás et al. (1998) hypothesise that cognitive events depend on activity involving thalamocortical resonant columns and present significant evidence in favour of their hypothesis. This, taken together with the action model and the conclusion of the present research, that the illness process of CFS involves a deep disruption to the action loop, suggests a hypothesis: the thalamus is the seat of felt meaning and phenomenality, while the output connections from the thalamus implement contact, the cortex is where the processing implied by the intellect takes place, the return connections from cortex to thalamus implement the feedback into felt meaning, and the adjacent regions of the brainstem implement action.

Given the structure of the action loop, that the thalamus is the only part of the brain with such a looped connection structure, and that injuries to the cortex have intellectual effects but do not cause changes in consciousness, while thalamus injuries tend to cause persistent and serious changes in consciousness, there appears to be very strong evidence that this looped structure of connections implements consciousness and the brain's action loop.

There is a long history of advances in the understanding of brain processes emerging from studies of people with brain injuries or dysfunctions. Identifying a population of people with a particular dysfunction that has observable phenomenological consequences makes future neurological work on the condition possible. This phenomenological research therefore calls for a strictly neurophenomenological investigation into the condition based on this evidence.

12.9 Prasangika Thought and Suffering

A treatment programme for CFS will require a conceptual basis from which to attend to CFS as a form of suffering. Given the resonance between the CFS discourse considered herein and the Prasangika definition of suffering, it may be useful to draw from this tradition in formulating a CFS treatment program.

Prasangika thought considers the desire to escape suffering to be one of the greatest impediments to resolving suffering. Pitkin comments: “In Buddhist terms, beings erroneously believe it is possible to avoid change and therefore pain—beings ‘think there is somewhere to go’ where they can keep their private personal selves from suffering. Even at moments where human beings act to address suffering, there is a subtle impulse to slip away from its difficulty, from the blow suffering deals to the illusion of permanent selves” (Pitkin 2001, p.240). Given this observation, what is remarkable within the recovered interviewees account is their decision to face their suffering by surrendering to it. The recovered interviewees unanimously emphasise the importance of this ‘surrendering self’ (see section 10.4) to the process of recovery.

Prasangika thought may also explain the compassion described by the ‘recovered self’ narrative (see section 10.5.3). “At the same time, it turns out that the freeing of the egocentric self from its burden of ignorance liberates a limitless outpouring of compassion for others—the possibility of the ethical” (Pitkin 2001, p.235). Could it be that by surrendering to the illness and becoming a more ‘virtual’ self the recovered interviewees experience a degree of freedom from the egocentric self that leads to compassion in the way the Prasangika identify? Several of the recovered interviewees claim the illness experience made them ‘better people’ in relationship with others. These interviewees were not able to describe how or why they felt this was the case. It could be that what they are referring to is the ‘possibilities of the ethical’.

Prasangika thought claims that liberation from suffering is brought about through an emptiness or virtuality of self. This emptiness is a freedom from the egoself and is also the basis of the ability to change. The Prasangika definition of suffering as an attachment to the egoself, then, also offers a solution to suffering. The CFS discourse this research has considered appears to support this definition of suffering. By exploring and interpreting CFS, this research has potentially lent insight into this form of suffering and to the nature of suffering generally.

12.10 Treatment Suggestions

This research provides a comprehensive first-person analysis of the experience of CFS that stands to contribute to the ability of a therapist to support a client in transforming their experience. Firstly, having more awareness of the structure of the experience will better equip

the therapist to assist the client in becoming aware and therefore opening up the potential for transformation. Secondly, by clarifying the nature of the experience this research can potentially enhance the therapist's empathy for the client's situation and this is likely to increase the success of therapy. Some CFS sufferers recover spontaneously. This research has elicited considerable detail of the process through which these sufferers do recover. In particular, there are a number of reported self-interventions which could be developed into parts of a treatment programme.

Genoud (2009) describes two general forms of meditation: Samatha, the development of concentration, and Vipassana, the cultivation of a meditative presence that allows for the discovery of the nature of mind.

In cultivating concentration Samatha cultivates the stability of mind. Samatha does not create presence: "as concentration implies grasping to an object, there is therefore a lack of presence, which can be partial or near-total" (Genoud 2009, p.118). Plausibly an (unconscious) excess of Samatha in an individual's consciousness could lead to an instability or brittleness of mind that would impede action and result in a lack of presence with which to be self aware. This potentially contributes towards an explanation for the inability to do and self-naïvety the ill interviewees describe.

Rather than the effortful intention of Samatha, the attitude that accompanies Vipassana is one of looking 'within' with awareness. Although clearly not the same, Vipassana is remarkably similar to the state from which the process of self-exploration the 'recovered self' describes as 'meditation' begins. It is as if entering into a state of objectless awareness provides the 'recovered self' with the space and freedom to witness thoughts, feelings and observations of circumstance.

The goal of Vipassana meditation is to increase reflective awareness of experience. In walking meditation the goal is specifically to increase awareness of bodily experience (Petitmengin and Bitbol 2009), including sensory awareness (Hurlburt 2009). If Vipassana meditation can be used to do so for sufferers of CFS then this stands to be an important treatment tool.

A reassessment and freedom from intention, which is similar to the freedom from intention in Vipassana, is also described by the recovered interviewees as a necessary step in their recovery process. In his description of the process of Vipassana, Genoud comments: "It is not that one needs to do something special. Rather, one simply needs to suspend any doing". The recovered interviewees describe a similar need to stop and reassess the doing that they have been habitually engaged in.

The similarities between aspects of the recovery process, as this was reported by the recovered interviewees, and the process of Vipassana meditation are striking. Similarly aspects of the illness process may reflect a misuse of concentration that could be addressed through the correct practice of Samatha. These observations suggest that a balanced training in both Samatha and Vipassana meditation could be utilised in a treatment programme for CFS to address the illness process.

Hendricks (2009) defines and discusses three levels of relationship to felt experience that occur during the focusing process: low, middle and high experiencing level. She summarises over a hundred studies of the effects of Gendlin's Focusing process. The evidence she presents shows that subjects who can achieve a high experiencing level are better able to discriminate physiological states, have an enhanced sense of bodily awareness and ability to relax physically, demonstrate increased immune function and the reduction of other effects of trauma. Hendricks comments: "physical illness or injury is a trauma. Utilizing Focusing to increase experiential involvement may be a key variable in the area of psychoneuroimmunology" (Hendricks 2009 p.140).

Moreover subjects who are able to achieve a high experiencing level are more creative, intuitive, flexible in the use of attention and are more able to connect with internally generated stimuli that enhance the performance of complex mental tasks. "Focusers can maintain concentration and withstand distractions while attending to an internal body sense" (Hendricks 2009 p.140). These findings suggest that when Focusing is used to a high experiencing level it may enhance various forms of contact, particularly contact with consciousness and proprioception. If Focusing to this level can be taught to CFS sufferers it stands to provide another tool for inclusion in treatment programs. This suggestion is supported by material discussed in this section regarding the differences between the recovered and ill interviewees CFS narratives and the recovered interviewees self-reported observations of key elements to their recovery process.

The definitions of experiencing level Hendricks presents provide a means to describe a general difference between the ill and recovered interviewees that I observed in the process of conducting the interviews. In my experience the recovered interviewees seemed to naturally and easily access the high experiencing level whereas ill interviewees were more likely to demonstrate a low or middle experiencing level until prompted to deepen their experiencing level. Including a process that monitors experiencing level in future research may be worthwhile. Hendricks provides an Experiencing Scale that can be used to measure experiencing level. If it is the case that experiencing level reflects illness state, as these observations suggest, then this

Experiencing Scale could be used as a diagnostic tool, incorporated into future research and used in a CFS treatment program.

Hendricks concludes: “our felt sense is OF our lived situations. It is our bodily sense of how all of ‘this’ situation is for us now. When our felt sense opens up, we say ‘Oh, that is what this situation is for me.’ It often implies steps of action” (Hendricks 2009 p.153). Illness is just such as situation and for CFS action is key. This is further reason to consider Focusing as an essential part of a CFS treatment program.

The transformative potential of the explicitation interview has been identified by numerous authors (Depraz 1999b; Depraz, Varela, and Vermersch 2000, 2003; Petitmengin 2006; Scharmer 2000; Varela and Shear 1999a) because of its relationship to the process of becoming aware: “becoming aware of a cognitive process also means opening up the possibility of transforming it” (Petitmengin 2006 p.260). This transformative potential includes the enhancement of emotional awareness and bodily experience (Petitmiengin and Bitbol 2009).

From the perspective of treating CFS what seems important about the gesture of becoming aware is the attentional disposition that evocation requires: the detached, receptive, yet alert quality of awareness that is necessary for letting come. This gesture has an uncanny resonance with what the recovered interviewees describe as the ‘meditative’ state of mind that contributes to their ability to recover (see section 10.5.2). By invoking this attentional disposition the individual can become open to appropriate connection with their situation and achieve better orientation to guide and create action.

Not only does this process hold potential for the treatment of CFS it also opens up a hermenutic process with those fields of knowledge that define the experience of illness. In the case of epilepsy Petitmiengin comments: “Looking beyond epilepsy, the taking into account of the subjective experience of patients, the possibility of studying it and describing it, could open up a vast field of research in the medical field, and considerably transform our vision of many illnesses” (Petitmengin 2006 p.260). In transforming how illness is understood such research would reveal assumptions about normality.

Preliminary work by Mathison and Tosey (2009) explores the combined application of the explicitation interview and neuro-linguistic programming (NLP) to the exploration of transformative learning. They conclude that “transformative learning, whether it be about a personal act of creation, or the complex, emergent quality of an individual’s insight, is unpredictable, embodied, and emergent” (Mathison and Tosey 2009 p.213). Their results include the finding that NLP in combination with the explicitation interview may assist in the evocation and elicitation of sensory experience: “Drawing on data from explicitation interviews with two

people, we have shown how NLP can assist with the evocation of experience, with the elicitation of sensory detail and with calibration of the interviewee's responses" (Mathison and Tosey 2009 p.213). Given that a significant difference between the ill and recovered interviewees appears to be their relationship with the sensory this approach needs to be considered for use in future research and may contribute an important tool in a CFS treatment programme.

For this same reason, the preliminary work on sensory awareness by Hurlburt, Heavey et. al. (2009) needs to be incorporated into future research. This work could be utilised in exploring the ill interviewees sense of a loss of world (see section 9.9) and the contrasting return of sensory awareness the recovered interviewees describe (see section 10.5) as one of the markers of their recovery process.

This approach may provide a means by which the specific aspects of sensory awareness that are disrupted in illness may be identified. The relationship between the degree and amount of sensory awareness and the forms of sensory awareness an individual engages in and health needs to be clarified. Exploring the relationship between the presence or absence of sensory awareness and the presence or absence of contact could be a means to test the hypothesis that CFS involves a lack of contact.

A treatment programme for CFS could include selected sensory stimulation. In the example of Ephraim's active creation and exploration of sensory stimulation (with his soup spoon), Hurlburt, Heavey et. al. (2009) draw attention to the difference between sensory stimulation that is passively received from the environment and the manipulation of the environment by the subject to produce sensory desired stimulation. This dynamic would need to be explored in a treatment program for CFS.

Andreas and Andreas (2009) describe three perceptual positions: self, other and observer, and a process for identifying and rectifying any misalignment between these positions. They comment: "in considerable research to date, *we have found no one who has their perceptual positions fully aligned in situations of difficulty*" (Andreas and Andreas 2009 p.221). Reflecting on the interview process I believe this statement would be true for the present research. Ill interviewees demonstrate a lack of alignment with the 'self position', particularly with respect to kinaesthetic perceptions. The characteristic posture of the ill interviewees that I observed in the interview process appears to reflect a being 'stuck' in the third, observer, position and is accompanied with being 'locked' in the visual mode. In contrast, recovered interviewees could easily access kinaesthesia from the first, self position and appeared to utilise this position more often. Future research would benefit from incorporating the observation of these perceptual positions into interview method.

Andreas and Andreas (2009) also claim that the use of their realignment process can create perceptual shifts that produce the reclamation of functioning: “some have experienced perceptual shifts as striking as regaining hearing loss, recovering peripheral vision, and improving vision, after using this process” (Andreas and Andreas 2009 p.222). If this process can be utilised in a treatment program for CFS sufferers this could address the ‘loss of world’ the ill interviewees describe and potentially accelerate the return of the sensory input that the recovered interviewees see as a mark of recovery. The process of aligning perceptual positions would need to be adapted for the CFS context. The authors comment that such adaption is possible. More attention may need to be paid to the kinaesthetic, the assessment and attribution of available ‘energy’, the enhancement of immune response and healthy digestion.

One result of perceptual realignment is that “we may find that we want different things – our goals might be different than when our inner world was out of alignment” (Andreas and Andreas 2009 p.230). This statement is akin to recovered interviewees descriptions of reassessing their goals (see section 10.4). This reassessment seems particularly difficult for ill interviewees and compounds the level of disruption to life planning processes the illness introduces. If the process of aligning perceptual positions can alleviate this difficulty then it is another means by which it may be valuable in the treatment of CFS. In sections 10.4.3-10.4.6 the recovered interviewees describe a sense of becoming more real, more whole, more integral and more aligned in mind and body as part of their process of recovery. There is an uncanny resonance between these passages and the effects of aligning perceptual positions and modes Andreas and Andreas (2009) describe. Investigating this relationship could be worthwhile both in future research and for the development of a CFS treatment program. It begs the question: how does the process of realigning perceptual positions potentially increase contact?

12.11 Conclusion

In section 12.2 the contributions of enaction and first-person methods to the current research were assessed. Both of these approaches were constructive for the present research. This warrants their use in future research and suggests that these approaches could be applied to other psychosomatic illnesses.

In section 12.3 the success of the participant recruitment process employed in the research was discussed. Studies of the condition involving both male and female participants and a broader population could draw from and extend this research. Various contributions to first person research methods are presented in section 12.3. As far as can be assessed through the method’s internal processes of verification these developments proved to be productive. The efficacy of these developments should be verified by future research.

A recursive action loop model for the production of viable, sustainable and meaningful action was developed in section 12.7. The implications of this model for cognitive science should be investigated since the model stands to shed considerable light on the nature of consciousness. As an approach to future research concerning the relation between action, perception and agency, neurophenomenology is strongly suggested by the findings of the present research. Specifically, in section 12.8, a neurophenomenological investigation into the dynamics of the thalamocortical system in the brain as the neurological implementation of the recursive action model is called for. Category theory was proposed as a foundation for the development of a mathematised phenomenology in section 12.5. This project needs to be pursued further since it may prove necessary for any neurophenomenological and neurological investigations of the action loop. A mathematised phenomenology, combined with the action loop model, could prove highly productive in artificial intelligence.

A treatment approach to CFS will require an understanding of suffering. In section 12.9 it is suggested that the Prasangika definition of suffering is a suitable candidate for this task. Phenomenologically-based treatment suggestions have been made in section 12.10. These should be studied as they may prove to be worth implementing in isolation. Ideally, however, this research suggests that these phenomenologically-based treatment approaches would best be combined with neurological and biomedical treatments. Such neurological and biomedical treatments would depend on the results of the neurophenomenological research suggested above, particularly the study of the dynamics of the thalamocortical system.

Appendices

A: Interview Schedule

Interview Schedule

1. How do you describe your current state of health?
2. How do you think about health more generally?
Has your illness changed this?
3. How do you prefer to refer to your illness?
4. How did you come to a diagnosis of ...?
5. How did you feel when you came to have a diagnosis?

6. Do you have an understanding of how your ... first started?
When did your ... first start? (stages)
Have you always considered ... to be the starting point of your ...?
7. What understandings of the causes of ... make the more sense or less sense to you?
8. Have you done any reading on ..., and if so, what of this did you find useful?
9. How does ... impact on your life?
10. How does ... impact on your financial, legal, social, career etc. status?

11. I'm really interested to know how you experience the fatigue in particular.
12. How have you expressed this fatigue to health practitioners?
Prompt for practitioners that they don't mention.
13. How have they responded to your expressions of fatigue?
14. How have health practitioners responded to your explanations of your ... more generally?
15. Has the M.E. support group played a role for you? If so, what role?

16. Has your state of health changed your relationship to your friends, family, or other close people? If so, how?
How (do you/have you) managed (this/these changed attitudes)?
17. Have you consulted any alternative practitioners? If so, what kind?
18. How do you compare the assistance they provided with traditional medical responses and help you have received?
19. What do you think would improve health practitioners ability to respond to people with ...?

B: Interview Schedule for Recovered Participants

Interview Schedule

1. How do you describe your current state of health?
2. How do you think about health more generally?
How did having ... change your understanding of health?
3. How do you prefer to refer to your illness?
4. How did you come to a diagnosis of ...?
5. How did you feel when you came to have a diagnosis?
6. Do you have an understanding of how your ... first started?
When did your ... first start? (stages)
Have you always considered ... to have been the starting point of your ...?
7. Do you have an understanding of when you recovered from your ...?
(sudden/gradual), catalyst, treatment, life(style) changes.
8. How would you describe the progress of the illness and recovering from it?
9. How do you think the health practitioner(s) you saw would describe the progress of your illness and your recovering from it?
10. What understandings of the causes of ... make the more sense or less sense to you?
11. How did ... impact on your life?
12. How did ... impact on your financial, legal, social, career etc. status?
How has ... changed your outlook on life?
13. How did you experience the fatigue in particular?
14. How did you express this fatigue to health practitioners?
15. How did they respond to your expressions of fatigue?
16. How did health practitioners respond to your explanations of your illness more generally?
17. Did the M.E. support group play a role for you? If so, what role?
18. Did you do any reading on ..., and if so, what of this did you find useful?
19. Did your state of health change your relationship to your friends, family, or other close people? If so, how?
How did you manage (this/these changed attitudes)?

20. Did your recovery from ... change your relationship to your friends, family, or other close people? If so, how?
21. Did you consult any alternative practitioners? If so, what kind?
22. How did you compare the assistance these alternative practitioners provided with traditional medical responses and help you received?

How would you now compare the assistance these alternative practitioners provided with traditional medical responses and help you received?
23. Has your ... had any lasting effects on your health? If so, what?
24. What do you think would improve health practitioners ability to respond to people with ...?
25. How do you think others view people with ...?
26. Is there anything else that you think would be important to understanding a woman's experience of ...?

C: Letter to General Practitioners

Blossom Hart
03-3488856

Address of GP

Dear Dr. *GP's Name*,

I am seeking your assistance to identify suitable women who may be interested in participating in a research project on chronic fatigue syndrome.

I am conducting a small scale exploratory study to investigate women's experiences of chronic fatigue syndrome where this has been diagnosed by themselves or by a medical practitioner. I am a postgraduate student at the University of Canterbury and my supervisor is Dr Victoria Grace, Senior Lecturer in Feminist Studies, who has a background in women's health research in New Zealand. Dr. Grace is collaborating with me in this study which is funded by a Health Research Council of New Zealand Summer Studentship. I have received ethical approval for the research from the SRHA Ethics Committee (Canterbury).

Would you be willing to assist by identifying suitable women who may be interested in participating in a one hour interview for this research? All that this would involve is identifying such individuals from your practice, and passing on a copy of the attached sheet to them, either in person or through the mail, over the next six weeks. It is then up to your patient to contact me if she is interested in participating.

The focus of this research is to gain insight into significant dimensions of the experience of CFS from a woman's perspective. The research is specifically concerned to analyse women's understandings of the condition and its etiology and to find out about approaches to treatment that have worked well or otherwise for them. The research is intended to contribute towards improving people's understandings of CFS and working towards better patient management.

This study does not involve any therapies, rather participants would attend semi-structured, open-ended interviews of approximately one hour duration held at a location convenient to them, for instance their home. There will be no expenses involved in your or your patients participation in this study and all participation is entirely voluntary. Participation in this study will not affect clients current or future health care. GPs will not be told which of their clients have chosen to participate in this study and no material that could personally identify GPs or participants will be used in any reports or publications from this study.

I have enclosed a copy of the information sheet and consent form to give you more information about the study. I will distribute this information to those women interested in possibly participating, once they have contacted me.

Thank you for considering this request. I will follow this letter with a phone call in a few days time.

Yours sincerely,

Blossom Hart

D: Information Sheet

Information Sheet: Women and Chronic Fatigue Syndrome xx/xx/xx

Researcher: Blossom Hart.
PhD Candidate
Department of Feminist Studies
University of Canterbury
Private Bag 4800
Christchurch
Contact phone number: (03) 3373345, 0800 397 467

Supervisor: Dr Victoria Grace, Dean of Arts and Senior Lecturer,
Department of Feminist Studies.

You are invited to take part in research into women's experiences of Chronic Fatigue Syndrome. The aim of this research is to gain insight into significant dimensions of the experience of CFS from a woman's perspective through listening to women's stories of their experiences. This research is intended to contribute towards improving people's understandings of CFS and working towards better patient management of CFS.

Your participation would involve attending an interview session which would be held at a location convenient to you. This could, for instance, be your home. You do not have to respond to all the questions, and you may stop the interview at any time. With your consent, interviews will be audio-taped. You may consider whether to take part in this study over the next week and you will then be contacted by the researcher, Blossom Hart. Participants for this research have been sought through GPs and a number of support groups.

The research does not involve any therapies; it involves talking to me in an interview about your experiences, in relation to a few questions. There will be no expenses involved in your participation. Your participation is entirely voluntary (your choice). You do not have to take part in this research, and if you choose not to take part in the research it will not affect your current or future health care. If you do agree to take part you are free to withdraw from the research at any time, without having to give a reason and this will in no way affect your current or future health care. Your GP will not be told that you have chosen to participate in the research nor that you have chosen not to if that is the case. No material that could personally identify you will be used in any reports or publications from the research. All records from the research, including consent forms, audio-taped interviews, and interview transcripts, will be stored in a locked filing cabinet. Only the researcher will have access to consent forms and only the researcher, supervisor and transcriber (who will be bound by a strict confidentiality agreement) will have access to audio-taped interviews and researcher and supervisor to interview transcripts. After the completion of this study these records will be kept for five years and then destroyed.

A summary of the results from this research will be made available to all participants who wish to receive it. If you wish to receive a summary of the results from this research please fill in the appropriate section of the Consent Form.

This research has received ethical approval from the Wellington Ethics Committee, Canterbury Ethics Committee and the University of Canterbury Human Ethics Committee.

If you have any concerns about the study you may contact the Wellington Ethics Committee, Wellington Hospital. Ph: (04) 385-5999 extn: 5185.

Please feel free to contact the researcher if you have any questions about this study.

E: Consent Form

Consent Form

Women and Chronic Fatigue Syndrome

I have read and understood the information sheet dated xx/xx/xx for volunteers taking part in the above study which is designed to explore women's experiences of Chronic Fatigue Syndrome. I have had an opportunity to discuss this study and I am satisfied with the answers I have been given. I understand that my participation in this research is voluntary (my choice) and that I may withdraw from the research at any time and this will not affect either my current or future health care. I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports or publications on this study. I have had time to consider whether to take part and I know who to contact if I have any questions about this study.

1. I consent to participating in an interview which will be audio-taped.
2. I consent to my interview being transcribed by a typist, of the researcher's choice, who will be bound by a strict confidentiality agreement.

Yes/No(Delete as appropriate)

2. I wish to receive a summary of the results. Yes/No (Delete as appropriate.)
(If yes, please provide an address for the summary to be mailed to)

.....
.....
.....

..... (full name)

Signature

Date

Researcher: Blossom Hart

Contact phone number: 0800 397 467, (03) 337-3345

F: Invitation to Participate

Research Topic: Women's Experiences of Chronic Fatigue Syndrome

You are invited to participate in a research project investigating women's experiences of Chronic Fatigue Syndrome.

The research is concerned to contribute to an improved understanding of how women understand and experience Chronic Fatigue Syndrome, what the key issues are for women in consulting health services for CFS, and how the health services can better assist them. I would value and opportunity to discuss your experiences on these topics.

Your participation would involve attending an interview session held at a location convenient to you. This could be your home.

If you are willing to participate in this study or find out more about it, please phone the researcher, Blossom Hart on 0800 379 467.

Researcher:

Blossom Hart
PhD Candidate
Department of Feminist Studies
University of Canterbury
0800 379 467, any time before 10.00pm

Supervisor:

Dr Victoria Grace
Dean of Arts and Senior Lecturer
Department of Feminist Studies
University of Canterbury

G: List of Node Names

1	Can't / Don't Want to Go Back	47	What I Want to Achieve
2	Change of Values Holism Slow Down	48	World Shrinking
3	Chronicity	49	Writing About ME
4	Confidence	50	Significant Other
5	Control	51	Isolation Loneliness
6	Discourses on Health	52	Family
7	Discourses on Wellness	53	Others Perceptions of ME
8	Empathy for Others	54	Others Perceptions Denial
9	Gendered Aspect	55	Others Perceptions According to Their Experiences
10	Honesty	56	Relating to, Communication With
11	Human Being vs Human Doing	57	Friend, Social Setting, Flatmates
12	Illness As Teacher	58	Mask on, Pretend
13	Invisible	59	Gp, Western Medicine
14	Interviewee Loses Track	60	Osteopath
15	Limitations, Boundaries, Overextend	61	Acupuncture, Tai Chi Chuan
16	Listen	62	Cranial Osteopath
17	Loss, Grief ,Change In Identity	63	Anxiety, Panic Attacks
18	Lucky Dip	64	Kidney Pain
19	Magic Pill	65	Brain Fog, Mental Concentration
20	ME Peoples Nature	66	Dyslexic Like Issues
21	ME Support Groups ANZMES	67	Brain Fog, Mental Concentration: Resulting Difficulties
22	ME vs Glandular Fever	68	Depression, Antidepressants
23	Meditation Awareness	69	Food, Digestion, Allergies
24	Mind, Body, Soul, Spirit	70	Hypoglycaemia
25	Name of Illness, Communicating it	71	Incontinence, Kidney, Bladder
26	Negative Affect	72	Headaches
27	Oppression	73	Temperature Issues
28	Parameters of the Illness	74	Heaviness, Sluggish Syrup
29	Perfectionism	75	Immune System, Infections Viruses
30	Physical Consequences on Mental	76	Difficulty Listening
31	Physical vs Mental	77	Memory
32	Positive Affect	78	Noise, Light Sensitivity
33	Pregnancy	79	Pain
34	Proactive	80	Aching Pain
35	Realising How Ill One Is	81	Difficulty Reading
36	Recognising The Need for Self Care	82	Sleep Disturbance
37	Relieving – Improving/Improving	83	Difficulty Talking
38	Safe and Protected	84	Tired, Fatigue, Exhaustion
39	Support Needed	85	Exhaustion, Giant
40	Surrender, Letting Go, Turning Point	86	Teary, Crying
41	Time	87	Exhaustion Most Extreme Case
42	Toxins, Chemicals, Poisons, Radiation	88	Exhaustion, Micropause vs Hyperspeed
43	Trauma	89	Difficulty Walking
44	Treatment Process	90	Weakness, Jelly Legs
45	Unsupported	91	Agoraphobia
46	WINZ		

92	Joint, Bone, Back, Limb Pain	141	Psychiatry
93	General and Crazy Pain	142	Weird Healer
94	Numb, Senses Closed Down	143	Massage Therapist
95	Difficulty Breathing	144	Homeopath
96	Lack of Stamina, Strength	145	Psychologist
97	Sex	146	Physiotherapist
98	Allergies (Not Food)	147	Gps vs Alternatives
99	Balance Clumsiness	148	Possible Improvements to Practice
100	Stress	149	Counselling
101	Tingling	150	Minister
102	Cramp	151	Ayurvedic
103	Sharp Pain	152	Iridologist
104	Burning Pain	153	Neurologist
105	Muscle Pain	154	Colour Therapist
106	Initial Collapse: Shutdown Bedridden	155	Herbalist
107	Initial Collapse: System Breakdown	156	Magnetic Things
108	Precursors, Before ME	157	Psychotherapy, Psychodrama
109	Post-Illness Experience of Wellness	158	Sometimes Inaccessible
110	Post-Illness Testing and Finding Improvements	159	Spiritual Growth Director
111	Relapse	160	Home Nurse Help
112	Social Impacts	161	Occupational Therapist
113	Impact on Life Opportunities	162	Experienced As Exposing
114	Emotional Impact	163	Endocrinologist
115	Impact on Physicaloutdoor Life	164	Rheumatologist
116	Impact on Relationships	165	Aromatherapy
117	Impacts	166	Kinesiologist
118	Career Impacts	167	Other People
119	Financial Impact	168	Neighbour
120	Legal Impacts	169	Work Setting
121	Impact on Status	170	Being Dependent
122	Stages	171	Understanding Empathy People
123	Initiators, Started	172	Dependants
124	Duration	173	Support or Lack Of
125	Symptoms	174	Energy
126	ME vs Depression	175	Body
127	Sweating	176	Cost Benefit Analysis
128	Nausea	177	Cyclic
129	Other Health Complications	178	Dreams
130	Fluid Retention	179	Emotions
131	Thirst	180	Rock
132	Palpitations	181	Exceptional Moments
133	Changes In Bodyweight	182	Exercise
134	Light-Headed, Unconscious, Dizzy	183	Frightening
135	Feeling Old	184	Hard Work Holding it Together
136	Tinnitus	185	How Positive Affect Works
137	Pale	186	Illness Dynamics
138	Health Practitioners	187	Interwellness Spiral
139	Naturopath	188	Independence
140	Chiropractor	189	Resistance to Medication or Treatment
		190	Multidimensionality

191	Normal	207	Accommodate
192	Qigong, Movement, Meditation and Massage	208	Fight it
193	Reading on ME	209	Importance of Recovered Role Models
194	Recovery Process	210	Making Sense of The Illness, Causes
195	Rest	211	Relation to Illness
196	Coping Strategies	212	Searching for Solutions
197	Spontaneous	213	Diagnosed by a Gp or Specialist
198	Suicide Death Giving Up	214	Self Diagnosis
199	Survival	215	Diagnosed by a Psychiatrist
200	Systemic Collapse	216	Diagnosed by an Alternative Practitioner
201	Un-Bounded Future Plans	217	Diagnosis
202	Weak Wei Qi	218	Diagnosis Process and Significance
203	Blame, Shame	219	Animals
204	Denial	220	Nowhere In The World I Belong
205	Not Contributing, In-Valid Failure		
206	Veracity, Validation		

H: List of Self Textual Invariants

ill self	focusing on wellness
analysing exploring I	meditating self
un defined redefined I	doing I
I can't imagine recover	resignation accept accomodate I
recovered compromised I	empathetic I
confused lost greif numb I	reclaiming the emotional I
illness as teacher	determined will I
mind/body split	dissociated I
isolated I	frightened terrified I/jester
frightened terrified I	I surrender fight
psychosomatic I	soul spirit
unconscious I	confidence selfesteem I
out of control I	imagining recovery I
destroyed I	greif over loss of previous self
ME perfectionist	half a life
connected I	psychodrama

I: List of Energy Textual Invariants

food digestion	drained away none not last
low lack	sleep rest lying down
recharging	ache hurt pain
heavy giant rock	breath
emotions	struggle huge effort
weakness	coping strategy
communication	intellectual energy
noise	read
life choice restrictions	B12 injections
general words	strength
consultations	stamina
spontaneity	got energy flow spontaneity
stuck blocked	minutae doing ordinary things
potatoes orange	reservoir battery
overextend	body not listening to
isolation	economic metaphors
energy from other holding my feet	relapse
sensitivity to light	agoraphobia
unpredictability	accomodate
mess chaos	new language
dying death	energy was unlimited
new relationship to energy	energy analysis management
collapse bang sudden	fighting counterproductive
gradual progress	post-illness lack
context work home	sex
powerlessness hopelessness	pretend mask
survive	limits boundaries testing
alive	planning
restriction	confidence
tinnitus	conserve reserve
allergies intolerances	clarity
numb	all from one basket
recovered	personal identity status

financial impact
loss
precious
grounded

symptoms relation to energy
energy is
imagining wellness

J: Table of Interview Quotation Statistics

Interviewee	Extracts	Extract word count	Tapes	Total transcript word count
I1	18	1314	2	22210
I2	9	915	2	19885
I3	8	297	1	18555
I4	3	343	1	14944
I5	30	2332	3	31715
I6	0	0	2	30663
I7	12	698	1	15194
I8	11	671	1	12722
I9	17	804	2	25440
I10	27	2471	3	36819
I11	18	1175	3	31847
I12	2	74	4	60761
I13	11	807	2	18343
I14	18	1282	3	50248
I15	14	831	3	23372
I16	2	161	1	12385
I17	4	230	1	15281
I18	14	973	2	26984
I19	5	210	2	34234
I20	8	623	2	30833
I21	31	2696	3	39847
I22	4	305	2	23818
I23	20	2208	1	9174
I24	1	32	1	6699
I25	7	469	1	10190
I26	15	998	3	46519
I27	10	1067	2	20324
I28	30	2188	4	41044
I29	1	64	5	46628
I30	9	681	2	27350
Total	359	26919	65	804028

‘Interviewee number’ is the same as used to refer to each interviewee throughout the thesis.

‘Extracts’ refers to the number of times the interviewee is quoted in the thesis, excluding section 7.6.

‘Extract word count’ is the number of words in the extracts. The extract counts do not include the long extracts in section 7.6.

‘Tapes’ records the number of C120 cassettes used to record each interviewee’s material. In the case where 4 tapes are used, this represents six interviews of approximately 90 minute duration. Note also that a C120 cassette records considerably more than 120 minutes.

‘Transcript word count’ is the total number of words in the transcripts of all each interviewee’s sessions, including both interviewer and interviewee.

Total is the sum of each column.

K: Examples of Neurophenomenological Research

The emergence of a naturalised phenomenology and a new science of consciousness places centre stage the philosophical problem of the ‘explanatory gap’. Neurophenomenology enlists the pragmatics of reciprocal constraints in an effort to bridge this gap. By drawing on those disciplines which have taken experience as their subject, neurophenomenology is refining a means of systematically evaluating experience. In acknowledging the phenomenality and irreducibility of the first-person and enlisting the second-person position, intersubjectivity and the role of empathy, neurophenomenology creates a basis for a viable relationship between the researcher and the subject of research for both qualitative and quantitative projects. This requires a clarification of the definitions of objectivity and subjectivity and their necessary relation. Likewise, neurophenomenology acknowledges the intersubjectivity of both objectivity and subjectivity. The crucial ontological and epistemological shift for the present research that neurophenomenology invites is to locate the intersection of object and subject, material and mental, phenomenal and natural within the lived, experienced, body. This provides a potentially productive platform for the consideration of psychosomatic illnesses such as CFS.

In comparison to the existing neurophenomenological research, the empirical data examined in the present research is focused on the first of the three threads of mutual constraint, on the phenomenality of CFS and has a strong exploratory focus (see section 5.2). Aspects of the method and the analysis of the empirical data attend to the second and third threads and draw directly from enactive cognitive science (see section 5.2 and chapter 4).

This appendix presents a review of existing neurophenomenological research. Research such as Thompson, Palacios and Varela (2002), which proposed an enactive approach to colour vision, prior to the development of neurophenomenology foregrounds the necessity for a methodological tool such as neurophenomenology. Presently, several authors are exploring the dynamical relationships between the neurological, biological and phenomenological aspects of experience (Cosmelli et al. 2004; Cosmelli, Lachaux, and Thompson 2007, forthcoming; Thompson and Varela 2001; Varela 1995; Varela et al. 2001). In a first empirical case study of the neurophenomenological methodology, Lutz (2002a) compares a study of the Mooney figure, using phenomenological isomorphism, to a neurophenomenological analysis of a 3D illusory autostereogram, employing the generative connections possible with the joint analysis of first and third-person data. In a second study, subjects were extensively trained in the task prior to testing and the gesture of reduction was adapted to the requirements of the investigation. Where subjects were not familiar with the gesture of reduction, this was aided by the experimenter through the use of open questions. Subjects practiced the task until phenomenological invariants

became stable (Lutz 2002a p.142). Subjects were active participants in the development of invariants (Lutz et al. 2002b, p.1587). Such an active intersubjective production of invariant categories by research subjects is also illustrated by work on binocular rivalry (Cosmelli et al. 2002). During trials, subjects' brain activity and retrospective verbal reports (using established invariants) of their cognitive context were recorded. Trials were then clustered according to the phenomenal invariants: steady readiness, fragmented readiness and unreadiness (Lutz 2002a p.143). The neurophenomenological study showed that these preparatory states modulated behavioural performance and were reflected in the evoked and induced neural synchronous patterns in stimulus response (Lutz et al. 2002b, p.1586). First-person reports were used to constrain dynamical neural signature (DNS) analysis and to interpret variability therein (Lutz et al. 2002b, p.1587). "By combining first-person data and the analysis of neural processes, the opacity in the brain responses (due to their intrinsic variability) is reduced and original dynamical categories of neural activity can be detected" (Lutz and Thompson 2003, p.45). First-person reports also modulated behavioural responses (Lutz et al. 2002b, p.1588-9). Lutz, Lachaux et al. (2002b) claim that these results "demonstrate the relationship between behavioural, neurophysiological, and first-person data" (Lutz et al. 2002b, p.1590). First-person reports bring clarity to the behavioural and neurophysiological data and behavioural and neurophysiological data validates the first-person reports. This study also exemplifies an intersubjective empathic openness (Depraz and Cosmelli 2003, p.187).

With respect to the Mooney figure study, Lutz concludes that, although phenomenological isomorphism allows for the use of first-person data in validating the link between the phenomenal and the natural, and first-person data can provide constraints that invalidate first-person models, phenomenological isomorphism preserves the separation between description and natural data (Lutz 2002a p.146). Implicit to phenomenological isomorphism is the assumption that the subject is passive and disembodied (Lutz 2002a p.148). The subject's responses are taken to confirm the parallels between the descriptive and the natural but do not have any direct input into the causal processes proposed (Lutz 2002a p.146).

Varela has demonstrated how the triple-braid of generative mutual constraints can be used to develop an understanding of temporal protention and retention and their affective dimensions (Varela 1997, 1999b, 1999c). This work has been further developed using schizophrenia as a means to investigate the neurophenomenology of the coherence of thought processes (Gallagher and Varela 2003).

Martinerie, Adam et. al. (1998) have used a neurophenomenological methodology in their investigation of how to predict the onset of epileptic seizures. Their results suggest that non-

linear processes in pre-ictal neural reorganisation can be used to predict 89% of seizure episodes as these processes reflect the sub-threshold neuronal recruitment that leads to seizure. Their initial study suggested that some epileptic patients may be able to avert seizure by using mental concentration or specific stimuli (Martinerie et al. 1998, p.1175). In Le Van Quyen and Petitmiengin's (2002) later research, the authors extend and concretely illustrate the efficacy of a neurophenomenological approach to epilepsy. Drawing on mathematical methods for analyzing complex systems (neurodynamics), the authors present experimental evidence "of 'upward' (local-to-global) formation of conscious experience and its neural substrate, but also the 'downward' (global-to-local) determination of local neuronal activity by situated conscious activity and its substrate large-scale neural assemblies" (Le Van Quyen and Petitmiengin 2002, p.170). Le Van Quyen and Petitmiengin (2002) claim the first-person data demonstrates that patients can identify the experiential events created by local epileptic activity prior to a seizure. The most striking case study they discuss illustrates how a patient was able to learn to identify epileptic spikes and reduce the number of spikes in order to avert seizure. Le Van Quyen and Petitmiengin (2002) argue that it is the relationship between the local and the global and an understanding of the brain as comprising complex networks of regions that makes such conscious intervention explicable.

Local neuronal activity at the level of an epileptogenic zone can produce upward effects, acting eventually in the global level of a moment of consciousness. The converse also seems to be the case, though less documented and more controversial: for example, a subject can voluntarily affect a local epileptic activity, as indicated by numerous patient reports and a few clinically reported cases. ... One can assume that such intervention is possible because the epileptogenic zones are embedded in a complex network of other brain regions that actively participate in normal large-scale interactions. From these observations, it follows that the global pattern of integration (the result of upward causation) can produce downward effects, acting eventually on the local level of epileptogenic zones, whose activity can thus be taken as an indicator of the downward influence (Le Van Quyen and Petitmiengin 2002, p.172).

These findings suggest that perception contributes very specifically to epileptic activity and used in downward causation this could contribute towards cognitive interventions for the control of seizure (Le Van Quyen and Petitmiengin 2002, p.173).

Le Van Quyen and Petitmiengin (2002) outline the difficulties they encountered in gathering first-person data from epileptic patients. They also describe the techniques and training used to aid patients in providing and refining the first-person reports (Le Van Quyen and Petitmiengin 2002, p.175-6). Le Van Quyen and Petitmiengin (2002) describe how the first-person experiential phenomena and the correlated third-person neurodynamical phenomena are mutually constraining.

The particular path that a dynamical system follows is determined by its current state in conjunction with its global intrinsic dynamics. This is not merely a formal description (as indicated above), but exhibits exactly the kind of simultaneous unfolding that phenomenological observation suggests (Varela 1999): first, there is “local-to-global” determination as a result of which every novel path has its own features, lifetime and domains of interactions. Second, there is “global-to-local” determination whereby global intrinsic characteristics of a system govern or constrain futures behaviour (Le Van Quyen and Petitmiengin 2002 p,177).

Le Van Quyen and Petitmiengin (2002) used the phenomenological reports of epileptic symptomatology to interpret the neurological data. Conversely, neurological data gathered simultaneously with patient reports was used to refine a patient’s ability to describe their experience. Finally, neurological data was used to allow patients to bring into conscious control neurological events. Similar research investigating the relationship between first-person experiences of various qualities of pain and their neural counterparts has been called for (Price, Barrell, and Rainville 2002).

Hanna and Thompson (2003) apply a neurophenomenological methodology in their investigation of the spontaneity of consciousness. By the spontaneity of consciousness, Hanna and Thompson (2003) refer to its inner plasticity and inner purposiveness:

We believe that subjective experience is partially constituted by its being at once underdetermined or uncontrolled by external influences (inner plasticity), and also self-determining or self-controlling (inner purposiveness). It is this dual subjective sense of inner plasticity and inner purposiveness that we mean to indicate with the term ‘spontaneity’ as applied to conscious experience (Hanna and Thompson 2003, p.137).

Hanna and Thompson (2003) claim that understanding phenomenological consciousness purely in terms of ‘what-it-is-like-for-an-organism’ is not enough to understand the spontaneity of consciousness. They make a distinction between the noetic¹¹⁴, act-aspect and the noematic¹¹⁵ object-aspect of consciousness. Hanna and Thompson (2003) discuss three examples of the spontaneity of consciousness: attention, the subjective experience of self-generative imagination and multistable visual perception. Spontaneity, they assert, refers to the ‘noetic’.

‘Spontaneity’ describes the inner plasticity and purposiveness that belongs to the noetic side of experience. In other words, it describes those aspects of consciousness that constitute it as a self-generative or self-organising process of experiencing (Hanna and Thompson 2003, p.139).

Hanna and Thompson (2003) draw strong parallels between the neurodynamics of multistable visual perception and binocular rivalry and behavioural and volitional spontaneity. Drawing from synergetics, they conclude that perceptual spontaneity arises from the instability and metastability of neurological dynamics. In this way, Hanna and Thompson (2003) demonstrate

¹¹⁴ “Of or pertaining to the mind or intellect; characterized by, or consisting in, mental or intellectual activity” (1989).

¹¹⁵ Noema is the “term first used by Husserl for that which is perceived or thought as the self experiences it” (1989).

how descriptions of first-person phenomena and the neurodynamics of perception are mutually constraining and illuminating. Their research also resonates with the need to acknowledge singularity and variability as important components of an intersubjective objectivity of consciousness (Depraz and Cosmelli 2003, p.190).

L: The Science of Consciousness: An Emerging Discipline

The science of consciousness is predominantly emerging from within cognitive science and the principal philosophical problem that faces both these disciplines is known as the ‘explanatory gap’ or the ‘hard problem of consciousness’. This problem and the ways in which several disciplines are contributing to its discussion are presented and reviewed in this appendix. What is at stake in these developments is the nature of objectivity and the relation between subjectivity and objectivity, a resolution of which is necessary to address the concerns of chapter 3. This theme is developed throughout chapters 5 and 6.

This research is an exploration of thirty New Zealand women’s experiences of CFS. The project involves exploring phenomenality, in Nagel’s (1979, p.165-180) terms, the ‘what it is like’ to have an experience. As such, the research is a study of the phenomena of experience within consciousness and a study of consciousness as a phenomenon. In this section I briefly review the history of the study of consciousness. This provides a background for the specific project of ‘naturalising phenomenology’ or, more specifically, ‘naturalising’ Husserlian phenomenology. Neurophenomenology is one approach to this project of ‘naturalisation’.

The project of studying phenomenological consciousness predates the formation of experimental psychology (Cohen and Schooler 1997). Introspection, the original method of psychology for the study of consciousness, produced several schools (Wundt and Titchener) but apparently failed to establish consistent methods for settling the differences in opinion between these schools with respect to the identification and categorisation of the elements of consciousness (Hurlburt and Heavey 2001; Thompson forthcoming). This fundamental disagreement between the schools of introspection occurred at the level of theoretical or causal interpretation: “one lesson to be learned from this debate, therefore, is not that introspection is a useless method for obtaining descriptive accounts of subjective experience, but rather that psychology needs to discriminate carefully between the description of subjective phenomena and causal-explanatory theorizing” (Thompson forthcoming). William James observed of these schools that they focused only on the sensations that arose from impoverished data (Thompson forthcoming). Vermersch (1999) further concludes that these early forms of introspection were misled by the apparent simplicity of their task and consequently did not make use of adequately rigorous and trained methods, particularly with respect to the role of mediation. In the face of the ‘objectivity’ of behaviourism, the introspective study of consciousness came to be considered ‘subjective’ and consequently outside the focus of science. The study of the phenomenality of consciousness became largely restricted to the clinical disciplines of psychoanalysis and psychotherapy (Hurlburt and Heavey 2001).

Velmans (2001) characterises the present milieu as one of transition in which a movement back towards the study of consciousness is being provoked by disillusion with a psychology that has not explained the phenomenality of experience. Increasingly, other scientific disciplines such as cognitive science, neuroscience and their biological counterparts are becoming interested in phenomenological consciousness (Hurlburt and Heavey 2001; Jack and Roepstorff 2002). The relation between mind and body and related psychosomatic phenomena are being investigated by these same scientific disciplines rather than being relegated to purely philosophical issues (Frith, Perry, and Lumer 1999). These enquiries are prompting the development of new methods and methodologies, both qualitative and quantitative. Precedent to this pragmatic process is the need for theoretical advance and many of these developments are supporting and culminating in the emergence of the new science of consciousness (Frith, Perry, and Lumer 1999; Crick and Koch 1998; Cohen and Schooler 1997; Velmans 1996). Despite the fragmented nature of the academic literature concerning CFS it is clear that this experience is one that affects both soma and psyche. I propose that the emerging science of consciousness offers an approach to researching this psychosomatic condition that allows for an engagement with both the psychological and somatic aspects of the experience.

What shape the science of consciousness will take is open to broad debate (Penrose, Longair, and Hawking 1997; Searle 1992; Varela, Thompson, and Rosch 1991; Jackendoff 1987; Flanagan 1992; Dennett 1991; Chalmers 1996). A central philosophical concern that emerges from this debate, articulated by Joseph Levine as the “explanatory gap”, reflects a problematic shortcoming within the discipline as it stands. Cognitive science, for instance, recognises that “for a whole set of cognitive systems, and for the human one in particular, things have appearances”, phenomenality (Barbaras 1999, p.1). As a discipline for the scientific study of mind, however, cognitive science: “is a theory of the mind without being a theory of consciousness. It is a theory of what goes on in our minds when they are cognizing without being a theory of what it is like to be a cognizing mind” (Botero 1999, p.7). In other words, cognitive science fails to account for phenomenological data. Since the emergence of the Galilean sciences produced a departure from the metaphysical traditions that predated them, this conflict in the strategies of explanation has arisen between the sciences of nature and the sciences of mind.

The project of naturalising Husserlian phenomenology is one attempt to attend to the ‘explanatory gap’. Here Roy, Petitot et al. (1999) comment that by ““naturalized” we mean integrated into an explanatory framework where every acceptable property is made continuous with the properties admitted by the natural sciences” (Dupuy 1999, p.2). The conditions required to realise such a naturalisation, given the contemporary revival of Husserlian phenomenology

and in the face of Husserl's own antinaturalist orientation, are under discussion (Dupuy 1999; Barbaras 1999; Botero 1999; McIntyre 1999; Salanskis 1999; Villela-Petit 1999). The projects discussed in the remainder of this section all attempt to bridge the 'explanatory gap' and enlist a Husserlian approach to varying degrees.

Studies on colour vision and the phenomena of perceptual completion offer classic examples of the need for cognitive science to consider phenomenological data (Villela-Petit 1999; Noë and O'Regan 2002a; Noë and Thompson 2002; Thompson 1995). Thompson, Noë and Pessoa argue that Dennett's purely third-person analysis of perceptual completion is only possible through a distorted treatment of the relation between the personal and the subpersonal (that is, whole organism and neural or bodily parts thereof) that fails to respect the conceptual autonomy of perceptual experience. Like Gibson, they argue that "the proper subject of perception is not the brain, but rather the whole embodied animal interacting with its environment" (Thompson, Noë, and Pessoa 1999 p.186). The body provides a spatial vantage point that contributes to the figure-ground structure of perceptual experience. Similarly, Van Gelder illustrates how consideration of phenomenological data with respect to the nature of "time consciousness" can inform cognitive science. He notes that "dynamical models exhibit exactly the kind of simultaneous unfolding that phenomenological observation suggests" (Van Gelder 1999, p.258). Such phenomenological data point strongly towards the need for cognitive science to develop a dynamical model of "time consciousness" as opposed to taking a computational approach. These examples represent an expanding number of approaches to bridging the 'explanatory gap' from the natural sciences to the social sciences.

Social scientists are also attempting to bridge the 'explanatory gap'. From a psychoanalytic perspective, the work of Shevrin (2000) considers how psychoanalytic method can be informed by neuroscience in the investigation of phenomena such as unconscious conflict, unconscious affect and unconscious signal anxiety (Shevrin et al. 1996). Shevrin urges the need for psychoanalytic theory to be informed by experimental findings, claiming that experimentation can support clinical experience and theory, whilst also urging cognitive psychological and neuroscientific investigations not to reduce unconscious processes purely to brain processes (Shevrin et al. 1996; Shevrin 2000).

Also building a bridge between psychoanalysis and neuroscience, Solms shows how third-person investigation can be informed by first-person accounts of, for instance, "right hemisphere syndrome" (Kaplan-Solms and Solms 2000; Solms 2000). The results are conclusions that are consistent with both the first and third-person explanations but contradict either of these in isolation. Solms argues that the combined use of neuropsychological and psychoanalytical

methods can potentially redress the imbalance in neuropsychology articulated by Oliver Sacks (1984). Such an approach can provide a voice for both the object and the subject of study in neurology.

In Pickering's view, the lack of subjectivity within psychology reflects a rigidity within the discipline that is a consequence of psychology's largely politically motivated reliance on the reductive methodologies of the natural sciences (Pickering 2000). Pickering argues that psychology requires a methodological and theoretical pluralism. Part of this pluralism requires of psychology, cognitive science and consciousness studies that these disciplines address the findings of first-person practices including Buddhist meditative techniques and qualitative phenomenological investigation. Pickering also suggests that psychology needs to attend to the methods of dynamic systems theory and the role of ethics and value within consciousness research (Pickering 2000, 1995). Such methodological pluralism will change the nature of psychology as a science and will force it to rethink its relation to the natural sciences.

Other theorists are concerned not only with observing but also developing and transforming consciousness (Fontana 2000; Henry 1996; Henry 1998; Henry 2000; Richardson 2000).

Increasingly, the science of consciousness is located as the principal discipline that can bridge the 'explanatory gap'. As Velmans demonstrates, what is at issue here is the nature of objectivity: "scientists can be objective in the sense of being "dispassionate", scientific method can also be "objective" in the sense that it follows well-specified, repeatable procedures, observation can be "objective" in the sense of *intersubjective*, but no observations are objective in the sense of being *observer-free*" (Velmans 2000a, p.12). This issue is most acute in the science of consciousness as it is one of the few sciences where the phenomena that are observed are also capable of making observations (Velmans 2000a). The natural sciences assume that the entities and events observed are located externally and observed exteroceptively by the experimenter. This allows experimental repeatability if experimenters follow systematic procedures as it is assumed that experimenters' access to the public (exteroceptive) phenomena observed is symmetrical. The assumption is that observation reports that are the same correspond to the same observations. Asymmetry arises in the study of consciousness, however, as the access to the phenomena observed for the subject of that experience and the experimenter are not equivalent. The subject has both interoceptive and exteroceptive access to the phenomena being observed. Velmans argues pragmatically that subjective observations of interoceptive phenomena should be treated in the same manner as the observation reports of exteroceptive phenomena. In other words, similar observation reports of interoceptive phenomena imply

similar experiences barring evidence to the contrary. It is a fallacy to assume that the observations of experimenters are any more 'public' or 'objective' than the apparently 'private' and 'subjective' observations of subjects (Velmans 2000a, 2000b).

Glossary

Abhidharma

“First elaborated as lists, the Abhidharma contains the earlier texts in which Buddhist concepts were developed, and hence was the source of most philosophical developments in Indian Buddhism.” (Dreyfus and Thompson forthcoming, 2007, p.7) Abhidharma also refers to “one of the oldest Bhuddist traditions, which can be traced back to the first centuries after the Buddha (566-483 BCE)” (Dreyfus and Thompson forthcoming, 2007, p.7).

Absence

“**Absence** is one of the terms in the category *presence/absence* which articulates the mode of semiotic existence of the objects of knowing. “In absentia” existence, which characterizes the paradigmatic axis of language, is called virtual existence” (Greimas and Courtés 1979, p.1).

Abstract

“Any term, whether belonging to a natural language or a metalanguage, is said to be **abstract** either because its semic density is low, in which case it is opposed to concrete, or because it does not have exteroceptive semes in its sememic composition, in which case it is opposed to figurative. At the level of discursive semantics, a distinction is drawn between the abstract (or thematic) component and the figurative component” (Greimas and Courtés 1979, p.1).

Actant

“An **actant** can be thought of as that which accomplishes or undergoes an act, independently of all other determinations. Thus, to quote L. Tesnière, from whom this term is borrowed, “actants are beings or things that participate in processes in any form whatsoever, be it only a walk-on part and in the most passive way”. From this point of view, “actant” designates a type of syntactic unit, properly formal in character, which precedes any semantic and/or ideological investment” (Greimas and Courtés 1979, p.5).

Actantial narrative schema

The actantial narrative schema is “a fundamental universal narrative structure that underlies all texts. There are six key actantial roles or functions arranged in three sets of binary opposition: subject/object; sender/receiver; helper/opponent. Together the six actants and their organization account for all the possible relationships within a story and indeed within the sphere of human action in general” (Martin and Ringham 2000, p.19).

Action

“1. **Action** can be defined as a syntagmatic organization of acts, without our having to make any *a priori* decision about the nature of this organization, whether it be an ordered or stereotyped sequence, or programmed by a competent subject. 2. In syntagmatic semiotics, action can be considered as the result of the conversion, at a given moment of the generative trajectory, of a narrative program, either simple or complex. In the case of a complex program, the various pragmatic narrative programs which compose it correspond to the acts which constitute the action. That is to say that an action is a filled-out narrative program, with the subject represented by an actor and the doing converted into a process. 3. Narrative semiotics does not study actions as such, but actions “on paper”, *i.e.* descriptions of actions. The analysis of narrated actions enables us to recognize stereotypes of human activities and to construct typological and syntagmatic models which take account of them. The extrapolation of such procedures and such models can form the basis for a **semiotics of action**” (Greimas and Courtés 1979, pp.6-7).

Action

“1. In the philosophical tradition which stretches back to scholasticism, an act is identified with “causing to be” and corresponds to the passage from potentiality to existence. This sort of definition, whose intuitive nature does not pass unnoticed, is extremely general. Not only can all the “events” which make up the web of narrative discourses be interpreted as acts, but discourse itself is an act, an organized sequence of cognitive acts. Consequently, it is essential to establish a model for the representation of the act that can be used in semiotic analysis and that can eventually form the starting point for a semiotics of action. 2. The intuitive definition of acting as “causing to be” shows that it contains two predicates that are in hypotactic relation. Its syntactic representation will thus assume the form of two utterances: an utterance pertaining to doing (=causing) and an utterance pertaining to state (=being). The former will govern the latter, which will be the object of doing. The canonical

representation of an act may be formulated by a modal structure either of the type F $[S_1 \rightarrow O_1 (S_2 \cup O_2)]$ or of the type F $[S_1 \rightarrow O_1 (S_2 \cap O_2)]$ and is recognizable at the level of surface narrative grammar. 3. The interpretation of this formula is simple: to act presupposes the existence of a subject and is identified with the modality of “doing”, producing a state (or change of state) that is formulated as the junction of an object with the subject, which may or may not be in syncretism with the subject of doing. Thus, to act partially corresponds to performance and presupposes a modal competence, considered as the potentiality of doing. This explains why an act is defined as the passage from competence to performance, with “passage” being interpreted syntactically as the modality of doing, which is conversion, at the level of anthropomorphic syntax, of the concept of transformation” (Greimas and Courtés 1979, pp.2-3).

Actor

“Historically the term **actor** has gradually replaced character (and *dramatis persona*), indicating thereby a greater desire for precision and generalization – a magic carpet or a business firm, for example, are actors – thus extending its use outside the purely literary. 2. Obtained by procedures of engagement and disengagement (which belong to the domain of enunciation), the actor is a lexical unit, nominal in type, which, once incorporated into the discourse, may receive, at the moment of its manifestation, investments of surface narrative syntax and discursive semantics. Its semantic content proper seems to consist essentially in the presence of the seme of individuation, which gives it the appearance of an autonomous figure in the semiotic universe. An actor may be **individual**, (for example, Peter), or **collective** (for example, a crowd), **figurative** (anthropomorphic or zoomorphic), or **non-figurative** (for example, fate)” (Greimas and Courtés 1979, p.7).

Actorialization

“What characterizes the procedure of actorialization is that it aims at establishing the actors of the discourse by uniting different elements of the semantic and syntactic components”. (Greimas and Courtés 1979, p.8)

Actorialization

“1. Along with temporalization and spatialization, **actorialization** is one of the components of discoursivization, and, like these two, is based on the implementation of the operations of engagement and disengagement. What characterizes the procedure of actorialization is that it aims at establishing the actors of the discourse by uniting different elements of the semantic and syntactic components” (Greimas and Courtés 1979, p.8).

Actualization

“1. From the point of view of the modes of semiotic existence, and within the linguistic framework, **actualization** corresponds to the passage from system to process. Thus, language is a virtual system which is actualized in speech and in discourse. In the same way, it can be said that a lexeme, which is characterized as a mere virtuality, is actualized thanks to the context in which it occurs in the form of a sememe. Used within the framework of the *virtual/actual* category, actualization is an operation by which a unit of language is rendered present in a given linguistic context; the actual existence (“in praesentia”) thus obtained is inherent in the syntagmatic axis of language. 2. Narrative semiotics has found it necessary to substitute for the traditional *virtual/actual* pair, the ternary articulation *virtual/actual/realized*, so that a better account can be given of narrative organizations. Thus, subjects and objects prior to their junction are in a virtual position; their actualization and their realization take place in accordance with two types of characteristic relations of the function; disjunction actualizes subjects and objects, conjunction realizes them. 3. From this point of view, actualization as an operation may correspond – insofar as it is brought about from a prior realization – to a transformation which effects the disjunction between subject and object. On the figurative level, it is, then, equivalent to privation. Depending on whether at the actorial level the subject of doing is different or not from the subject, in a situation of lack there will be either a transitive actualization (figurativized by dispossession) or a reflexive actualization (renunciation). The term **actualized value** refers to any value invested in the object at the moment, or in the syntactic position, when the object is in a disjunctive relation with the subject” (Greimas and Courtés 1979, p.9).

Afferent

“Afferent: designating nerves or neurons that convey impulses from sense organs and other receptors to the brain or spinal cord, i.e. any sensory nerve or neuron” (Martin 1994, p.13).

Aphoria

“**Aphoria** is the neutral term of the thymic category articulated into *euphoria/dysphoria*” (Greimas and Courtés 1979, p.15).

Asthenia

Asthenia n. weakness or loss of strength. Asthenic adj. describing a personality disorder characterised by low energy, susceptibility to physical and emotional stress, and a diminished capacity for pleasure. (1994)

Being

“Outside of its ordinary use, the lexeme **being** is used, in semiotics, with at least three different meanings: (a) It serves as copula in utterances of state; thus, by predication, it joins to the object properties considered “essential”. On the level of semantic representation, such properties are interpreted as subjective values in junction with the subject of state; (b) It is used as well to name the modal category of veridiction: *being/seeming*; (c) Finally, it designates the positive term of the immanence schema: it is then in a relation of contrariety with seeming” (Greimas and Courtés 1979, p.22).

Being-able

“1. In the framework of a theory of modalities, **being-able** (*to do* or *to be*) can be considered as the name of one of the possible predicates of the modal utterance governing a descriptive utterance of doing or of state. Although it is a concept which cannot be defined, it nonetheless can be interdefined in a chosen and axiomatically postulated system of modal values” (Greimas and Courtés 1979, p.23).

Canonical narrative schema

The canonical narrative schema “presents a universal prototype for the structure of narrative. It is composed of three tests: the qualifying test, the decisive test and the glorifying test, which unfold in logical succession. These tests are preceded by the stage of manipulation or contract” (Martin and Ringham 2000, p.32). See also: (Greimas and Courtés 1979, pp.203-206)

Certainty

“**Certainty** is the name of the positive term of the epistemic modal category the syntactic definition of which is *believing to be*. As opposed to evidence, certainty presupposes the exercise of interpretive doing, of which it is one of the possible consequences” (Greimas and Courtés 1979, p.28).

Chrononym

“Certain semioticians (G Combet) have proposed to introduce alongside toponym and anthroponym the term **chrononym** to designate specific lengths of time, such as “day”, “spring”, “coffee break”. This word can advantageously replace that of “period”. Together with anthroponyms, chrononyms help to establish a historical anchoring which aims at constituting the simulacrum of an external referent and to produce the meaning effect “reality”” (Greimas and Courtés 1979, p.29).

Cognitive

“1. The adjective **cognitive** is used, in semiotics, as a specifying term by reference to various forms of articulation of knowing – production, manipulation, organization, reception, assumption, etc. 2. Hierarchically superior to the pragmatic dimension which acts as its internal referent, the **cognitive dimension** of the discourse is developed in parallel fashion with the increase in knowing as a cognitive activity attributed to the subjects installed in the discourse. If the pragmatic dimension – along with the sequence of programmed actions proper to it – does not necessarily imply the cognitive dimension, the reciprocal is not true: the cognitive dimension, which can be defined as the taking in charge, by knowing, of pragmatic actions, presupposes them” (Greimas and Courtés 1979, p.32).

Coherence

“The term **coherence** is used colloquially to characterize a doctrine, a thought system, or a theory, all of the parts of which hold solidly together” (Greimas and Courtés 1979, p.35).

Competence

“3. The distinction between what competence is and what it bears on (that is, its object, which, in the case of linguistic competence, is identified, once it has been described, with grammar) allows us to consider competence as a modal structure. As is clear, here we return to the whole set of problems concerning act. If act is a “causing-to-be”, competence is “*that* which causes to be”, that is, all the prerequisites and presuppositions which make action possible. Thus if the problem of competence in

the (vast, but nonetheless limited) linguistic domain is transposed to that of semiotics, it can be said that every sensible behaviour or every sequence of behavior presupposes, on the one hand, a virtual narrative program and, on the other, a particular competence which makes its carrying out possible. Competence, thus conceived, is a **modal competence** which can be described as a hierarchical organization of modalities (it will be based, for example, on a willing-to-do or a having-to-do, governing a being-able or a knowing-how-to-do). It must be distinguished from **semantic competence** (in the broadest sense of the word semantic, the one which is used, for example, when it is said that the deep structure of language is logico-semantic in nature) the simplest form of which is the virtual narrative program. Once joined, these two forms of competence constitute what can be called the **subject's competence**" (Greimas and Courtés 1979, p.45).

Contact

"Having the six senses means that each sense is able to contact its sense field, its appropriate object. Any moment of consciousness involves contact between the sense and its object (contact is an omnipresent mental factor ...); without contact, there is no sense experience" (Varela, Thompson, and Rosch 1991, p.113).

Content

"The term content is thus synonymous with Saussure's overall signified" (Greimas and Courtés 1979, p.57).

Contract

"In the very general sense, **contract** can be understood as the fact of establishing, of "contracting" an intersubjective relationship which has as its effect the modification of the status (being and/or seeming) of each of the subjects involved. Even though this intuitive notion cannot be defined rigorously, we need nevertheless to posit the term contract so as to determine progressively what are the minimal conditions under which the establishment of "entering into a contract" between two subjects takes place. These conditions can be viewed as being presupposed by the establishment of the structure of semiotic communication. It is indeed necessary to recognize, hidden under the contract, this "phatic communication" which constitutes the necessary and preliminary undergirding for any communication and which seems to involve both a tension (a well-disposed or a mistrustful expectation) and a relaxing (as a kind of response to the expectation). Indeed, the establishment of the intersubjective structure is at once, on the one hand, an opening toward the future and toward possibilities for action and, on the other hand, a constraint which somehow limits the freedom of each of the subjects. We propose to use the term **implicit contract** to designate this set of preliminary components on which the intersubjective structure is based" (Greimas and Courtés 1979, p.59).

Contradiction

"1. The relation **contradiction** is the relation which exists between two terms of the binary category *assertion/negation*. Since the names 'relations', 'term', 'assertion', and 'negation' refer to non-definable concepts, the above definition is located on the deepest and most abstract level of the semiotic network. 2. Contradiction is the relation which is established, as a result of the cognitive act of negation, between two terms of which the previously-positing first one is made absent by this operation while the second term becomes present. Thus it is a relation of presupposition at the level of the posited contents: the presence of the other, and vice-versa. 3. As one of the constitutive relations of the semantic category, contradiction defines the two schemas ($s_1 - \sim s_1$, $s_2 - \sim s_2$) of the semiotic square. The terms of the schema are said to be contradictory to each other" (Greimas and Courtés 1979, p.61).

Desire

"1. **Desire** is a psychological term often opposed to will. Properly speaking, it therefore does not belong to semiotic terminology. From the semantic perspective, it can, with fear, constitute a pair of contraries – the category called by R. Blanché *philia/phobia* – in which fear is not a non-wanting but a contrary wanting. On the figurative plane the two terms can be formulated in various ways. Thus, for instance, desire is often expressed by a forward movement (a quest for the object of value) while fear is manifested by a backward movement (running away). 2. Semiotics far from denying the "reality" of desire, views it as one of the lexicalizations of the modality of wanting. Thus semiotic research should involve the development of a logic of wanting (parallel to deontic logic), in which the terms desire and will would designate the variables of wanting, and which would then be correlated with more complex semantic structures" (Greimas and Courtés 1979, p.76).

Discourse

“1. In the first perspective, the concept of **discourse** can be identified with that of semiotic process. In this way the totality of the semiotic facts (relations, units, operations etc.) located on the syntagmatic axis of language are viewed as belonging to the theory of discourse. When one has in mind the existence of two macrosemiotic systems – the “verbal world” manifested in the form of natural languages, and the “natural world” as the source of non-linguistic semiotic systems – the semiotic process appears as a set of **discursive practices**: linguistic practices (verbal behavior) and non-linguistic practices (signifying somatic behaviour manifested by the sensory orders). When linguistic practices alone are taken into consideration, one can say that discourse is the object of knowledge considered by **discursive linguistics**. In this sense discourse is synonymous with text. ... On the other hand – by extrapolation and as an hypothesis which seems to be fruitful – the terms discourse and text have also been used to designate certain non-linguistic semiotic processes (a ritual, a film, a comic strip are then viewed as discourses or texts). The use of these terms postulates the existence of a syntagmatic organization undergirding these kinds of manifestations” (Greimas and Courtés 1979, p.278).

Dispossession

“Located on the figurative level, **dispossession** represents the situation of the subject of an utterance of state when that subject is derived of the object of value by a subject of doing other than itself. Thus it corresponds to a transitive disjunction from the object, taking place at any point in the narrative trajectory. Together with renunciation, dispossession is one of the two possible forms of deprivation, which can be viewed, taken as consequence, as sub-components of a test” (Greimas and Courtés 1979, p.91).

Doing

“The distinction that we have established between utterances of **doing** and utterances of state, even if it refers intuitively to the dichotomy change/permanence, is an *a priori* and arbitrary formulation, which permits the construction of a surface narrative syntax. As the predicate-function of such an utterance, doing is to be considered, in an anthropomorphic syntactic language, as the conversion of the transformation relation. 2. The modal character of doing needs to be recognized. According to our definition – which seems to us to be the least restrictive – a modality is a predicate governing and modifying another predicate (or an utterance which has as object-actant another predicate). In this perspective, any case of doing – whether it be a case of an instrumental doing (causing-to-be), or a manipulative doing (causings-to-do), of a doing which constructs, transforms, and destroys things, or of a factitive doing which manipulates beings-appears as the predicate-function of a modal utterance governing another utterance. 3. Along the two dimensions of narrativity (and of the activities that it is supposed to describe and organize), the pragmatic dimension and the cognitive dimension, two sorts of doing will be distinguished: **pragmatic doing** and **cognitive doing**. This opposition, which at first appears to be self-evident, is nonetheless not syntactic in nature and asserts itself only at more superficial levels of language. Thus, pragmatic doing seems to be distinguished from cognitive doing by the somatic and gestural nature of its signifier, and also by the nature of the semantic investments that the objects concerned by the doing receive (the objects of pragmatic doing being descriptive values, cultural values, in a word, non-modal values). However, the somatic or gestural signifier is sometimes placed at the service of cognitive activities (in the communication or construction of objects, for example). Thus, it is G. Dumézil’s third function which best describes pragmatic doing. 4. The distinction, in the cognitive dimension, between **narrative doing** and **communicative doing** is syntactic in nature. Communicative doing is a “causing-to-know”, that is, a doing which has cognition as the object of value that it aims to bring into conjunction with the receiver. When the axis of communication has thus been recognized, it is then possible to introduce new distinctions – the proliferation of which must not exceed the real needs of the analysis – founded on semantico-syntactic criteria. Thus, first of all, an **informative doing** will be recognized, defined by the absence of any modalization, as the communication of the object of cognition in its (theoretically) pure state. The informative doing can then be viewed as the articulation of an **emissive doing** and a **receptive doing**. The latter can be either **active** (listening, looking-at) or **passive** (hearing, seeing). It is along the same axis of communication that the distinction – which seems to us fundamental for a typology of discourse – between **persuasive doing** and **interpretive doing** appears, thanks to the modalizations and complexifications of the programs of doing which are its results. 5. Narrative doing – which corresponds, in our view, with what could improperly be designated as a “syntagmatic understanding” – constitutes a vast and open field for analysis and reflection, whose importance, through its relations with cognitive psychology, can only increase. Preliminary studies, in the area of discourse concerning scientific topics, have led to a distinction between a **taxonomic doing** (with its **comparative** and

taxonomic aspects) and a **programming doing**” (Greimas and Courtés 1979, pp.93-94).

Dysphoria

“**Dysphoria** is the negative term of the thymic category which serves to valorize the semantic microuniverse – by establishing the negative values – and to transform them into axiologies. The thymic category is articulated as *euphoria/dysphoria*, and includes, as a neutral term, *aphoria*” (Greimas and Courtés 1979, p.96).

Efferent

“Efferent: designating nerves or neurons that convey impulses from the brain or spinal cord to muscles, glands and other effectors; i.e. any motor nerve or neuron” (Martin 1994, p.207).

Engagement

“1. **Engagement** is the inverse of disengagement. The latter is the effect of the expulsion from the domain of the enunciation of the category terms which serve as support for the utterance, whereas engagement designates the effect of a return to the enunciation. This effect is produced by the suspension of the opposition between certain terms belonging to the categories of actor and/or of space and/or of time, as well as by a negation of the domain of the utterance. Every engagement thus presupposes a disengagement operation which logically precedes it” (Greimas and Courtés 1979, p.100).

Epoche

“The use of the term ‘epoche’ in neurophenomenology is derived from the Greek term *epokhè* and is influenced by Husserl’s appropriation of the Greek term” (Depraz, Varela, and Vermersch 2003, p.25).

Euphoria

“**Euphoria** is the positive term of the thymic category, which serves to valorize semantic micro-universes by transforming them into axiologies. *Euphoria* is opposed to *dysphoria*. The thymic category includes, in addition, as a neutral term, *aphoria*” (Greimas and Courtés 1979, p.110).

Experiencer

“Despite the atmosphere of debate that surrounded some issues, there was unanimous agreement on the more experientially direct claim that each of the senses (eye, ear, nose, tongue, body, and mind) had a different consciousness (recall Jackendoff) – that is, at each moment of experience there was a different experiencer as well as a different object of experience.” (Varela, Thompson, and Rosch 1991, p.69)

Expression

“Following L. Hjelmslev, we designate by **expression** plane the Saussurian signifier taken in the totality of its articulations, as the recto of a page whose verso would be the signified. ... The expression plane is in a relation of reciprocal presupposition with the content plane, and their union, in the language act, corresponds to semiosis. The distinction between these two planes of language is, in Hjelmslevian theory, logically anterior to the division of each into form and substance. The expression form is thus phonology’s object of study, whereas the expression substance belongs to phonetics” (Greimas and Courtés 1979, p.113). This definition of expression is consistent with the enactive approach.

Figurativized

“The discourse is said to be figurativized at the moment when the syntactic object (0) receives a semantic investment which will permit the enunciatee to recognize it as a figure, as an ‘automobile’ for example: SUO (: automobile) v (: power). The discourse which expresses the quest for the automobile, the exercise and, possibly at the end, the recognition by another of the power which it allows to be manifested is a figurative discourse” (Greimas and Courtés 1979, pp. 118-9).

General Practitioner

A general practitioner is “a doctor (also known as a *family doctor* or *family practitioner*) who is the main agent of primary health care, through whom patients make first contact with health services for a new episode of illness or fresh developments of chronic diseases” (Martin 1994, p.269).

Glorifying test

“A discursive figure linked to the narrative schema, the **glorifying test** is situated in the cognitive

dimension; such is not the case for the qualifying and the decisive (or main) tests, which it presupposes. It appears in the narrative when the decisive test has been carried out in the secret mode. As a cognitive performance (and persuasive doing) of the subject, it call for-on the corresponding plane of competence-a *being-able-to-cause-to-know* figurativized by the mark. As the sender's cognitive sanction, within the contractual component of the narrative schema, it is the equivalent of recognition" (Greimas and Courtés 1979, p.137).

Helper

"**Helper** designates the positive auxilient when this role is assumed by an actor other than the subject of doing: it corresponds to an individualized being-able-to-do which, help to bear on the carrying out of the subject's narrative program. It is paradigmatically opposed to the opponent (which is the negative auxilient)" (Greimas and Courtés 1979, p.141).

Hermeneutics

"Hermeneutics, the 'art of interpretation', was originally the theory and method of interpreting the Bible and other difficult texts. Wilhelm Diltthey extended it to the interpretation of all human acts and products, including history and the interpretation of human life. Heidegger, in *Being and Time* (1927), gave an 'interpretation' of the human being, the being that itself understands and interprets" (Inwood 1998, p.389).

Heuristic

Heuristic in the sense of "serving to find out or discover" (1989).

Immanence

"1. The autonomy of linguistics – justifiable by the specificity of its object, insisted upon by Saussure – has been reaffirmed by Hjelmslev under the form of the **immanence principle**. Since the object of linguistics is form (or natural language in the Saussurian sense), any recourse to extra-linguistic facts much be excluded, because it breaks down the homogeneity of the description. 2. The concept immanence participates, as one of the terms, in the *immanence/manifestation* dichotomy. The manifestation logically presupposes the manifested, that is to say the immanent semiotic form" (Greimas and Courtés 1979, p.151).

Implication

"2. Considered as an act of implying, implication consists, for us, in the assertive calling up of the presupposing term, having as its effect the appearance of the presupposed term. The presuppositional relation is thus envisaged as logically prior to implication: the "if" would not find its "then", if the latter did not already exist as the presupposed" (Greimas and Courtés 1979, p.152).

Inchoate

"Inchoateness is an aspectual seme which shows the beginning of a process: it is part of the aspectual configuration inchoateness/durativeness/terminativeness, and its appearance in the discourse allows the realization of the entire series to be foreseen or expected" (Greimas and Courtés 1979, p.154).

Independence

In this section, the terms **independence** and **submission** are used in their technical sense as relating to relationships within the semiotic square for being-able. See: (Greimas and Courtés 1979, p.23-4).

Individuation

"2. In narrative and discursive semiotics, the concept of individuation is part of the problems connected with the actor – be it individual (a character) or collective (a group) – insofar as the actor is defined as made up, at a given moment of the generative trajectory, of structural properties which are both syntactic and semantic in nature" (Greimas and Courtés 1979, p.155).

Interoception

"Interoceptive doing designates actions that are *non-figurative*, that is, actions that take place inside the mind and relate to an internal world, such as thinking, remembering or feeling. The term can be contrasted with that of exteroceptive doing. This designates actions that are concrete and relate to the external physical world such as seeing, eating, jumping etc" (Martin and Ringham 2000, p.76). Cept is a root meaning to grasp and inter is a prefix meaning within thus interoception is the process of grasping that which lies within.

Iipseity

Iipseity refers to “personal identity and individuality; selfhood” (1989).

Isotopy

“1. A.J. Greimas has borrowed the term **isotopy** from the field of physics and chemistry and has transferred it to semantic analysis by giving it a specific signification in view of its new field of application. As an operational concept isotopy at first designated iterativity along a syntagmatic chain of classemes which assure the homogeneity of the utterance-discourse. From this point of view it is clear that the syntagm joining together at least two semic figures may be considered the minimal context necessary for establishing an isotopy. Such is the case for the semic category that subsumes the two contrary terms. Taking into account the trajectories to which they can give rise, the four terms of the semiotic square are called **isotopys**. 2. With regard to the generative trajectory of the discourse and the distribution of its components, we distinguish between the **grammatical isotopy** (the syntactic isotopy, understood in semiotic terms) with the recurrence of categories pertaining to it, and the **semantic isotopy**, which makes possible a uniform reading of the discourse as it results from the partial readings of the utterances making it up and from the resolution of their ambiguities which is guided by the search for a single reading” (Greimas and Courtés 1979, pp.163-4).

Junction

“In narrative semiotics the name disjunction is kept for designating paradigmatically one of the two terms (the other being conjunction) of the category **junction**. This category is defined on the syntagmatic plane as the relation between subject and object, that is, as the function constitutive of utterances of state” (Greimas and Courtés 1979, p.91).

Lack

“In the canonic narrative schema as derived from Propp, the lack is the figurative expression of an initial disjunction between the subject and object of the quest: the transformation which brings about their conjunction (or realization) plays a pivotal narrative role (making possible the passage from a state of lack to its liquidation) and corresponds to the decisive test (or performance). Thus we see that the **lack** is not actually a function but a state which, admittedly, is the result of a prior operation of negation (situated at the deep level)” (Greimas and Courtés 1979, p.169).

Lexeme

For the purposes of this analysis, a lexeme may be defined as “the totality of possible or virtual meanings attached to a particular word” (Martin and Ringham 2000, p.80). For a broader definition the reader may refer to Greimas and Courtés’s (1979, pp.172-5) discussion of the lexeme and lexicology.

Lexical cohesion

“Lexical cohesion occurs when two (or more) words in a text are semantically related, that is, they are related in terms of their meaning or content. Common devices of lexical cohesion are: pronouns, repetition, collocations and synonyms” (Martin and Ringham 2000, p.81).

Mindfulness/awareness

“The practice of recognizing emptiness in every moment is known as the practice of mindfulness/awareness or samatha-vispasnya. Essentially a radical not-doing, it is traditionally understood as a universal practice, but despite having been refined and explored for 2500 years by over half the world, it was never discovered independently in the West. Instead of a space for the human in the analyst’s studio required by psychoanalysis, samatha-vipasnya creates the space through non-action, which includes nonresponse to language” (Varela 1992, p.66).

Mononucleosis

Mononucleosis: The condition in which the blood contains an abnormally high number of mononuclear leucocytes (monocytes) (1994)

Neurasthenia

Neurasthenia n. A disorder characterized by feelings of fatigue and lassitude

Neurasthenia

Neurasthenia n. a set of psychological and physical symptoms, including fatigue, irritability, headache, dizziness, anxiety, and intolerance of noise. It can be caused by organic damage, such as head injury, or it can be caused by neurosis (1994)

Noema

Noema is the “term first used by Husserl for that which is perceived or thought as the self experiences it” (1989).

Object of value

“The object – or **object of value** – is then defined as the locus wherein values (or qualifications) are invested and to which the subject is conjoined or from which it is disjoined” (Greimas and Courtés 1979, p.217).

Ontogeny

Ontogeny refers to the “origin and development of the individual being” (1989).

Opponent

“When the role of negative auxilant is taken up by an actor different from the actor of the subject of doing, it is called **opponent** and corresponds then, from the point of view of the subject of doing, to an individualized *not-being-able-to-do* which, under the form of an autonomous actor, thwarts the realization of the narrative program in question” (Greimas and Courtés 1979, p.220).

Performance

“5. Performance, considered as the narrative program of the competent subject, one that acts (by itself), can serve as a starting point for a semiotic theory of action: it is known that every narrative program is capable of expansion under the form of instrumental narrative programs which presuppose each other in the framework of a base program. Interpreted, on the other hand, as a modal structure of doing, the performance – called **decision** when it is located in the cognitive dimension, and **execution** in the pragmatic dimension – allows us to envisage further theoretical developments” (Greimas and Courtés 1979, p.228).

Phylogeny

Phylogeny refers to “the genesis and evolution of the phylum, tribe, or species; ancestral or racial evolution” (1989) or history.

Pragmatic

“The pragmatic dimension, recognized in narratives, corresponds roughly to the descriptions which are made there of signifying somatic behaviors, organized into programs and taken by the enunciate as ‘events’ independently of their possible utilization at the level of knowing” (Greimas and Courtés 1979, p.240).

Prajna

Prajna, or wisdom, provides a route to knowledge that does not invoke the subject/object dichotomy. *Prajna* is not knowledge *about* anything, rather, through an attitude of letting go, “the mind’s natural characteristic of knowing itself and reflecting its own experience can shine forth” (Varela, Thompson, and Rosch 1991, p.26).

Presence

“In a semiotic perspective presence (“being-there”) is considered as a determination attributed to an entity which transforms it into an object of knowing of the cognitive subject. Such a meaning, essentially operational, established in the theoretical framework of the transitive relation between the knowing subject and the knowable object, is very extensive: all possible objects of knowing are present in this case; and presence is identified in part with the notion of semiotic existence” (Greimas and Courtés 1979, p.242).

Proprioceptor

A proprioceptor is “any receptor, as in the gut, blood vessels, muscles, etc., that supplies information about the state of the body” (Makins 1992, p.1072), therefore, proprioception is the sense of bodily state.

Qualia

“The terms ‘quale’ and ‘qualia’ (plural) are most commonly understood to mean the qualitative, phenomenal or ‘felt’ properties of our mental states, such as the throbbing pain of my current headache, or the peculiar blue afterimage I am experiencing now” (Levin 1998, p.863).

Receiver

“1. In information theory, the **receiver** (as opposed to the sender) designates the domain in the process of communication where the message is received. In this sense the receiver is not necessarily the one to which the message finally must be transmitted. 2. In semiotics, and for any type of communication (verbal or non-verbal), the term addressee (taken from R. Jakobson) is used with a comparable meaning. In the particular case of verbal communication, the receiver (to which can be linked the concepts of reader and listener) will be called enunciate. 3. Beyond the simple question of terminology, the difference between communication theory and the semiotic point of view resides, in the first case, in that the receiver represents an empty position (this is consistent with a mechanistic perspective), whereas, in the second case, the addressee corresponds to a subject endowed with competence and apprehended at a given moment of its becoming, in a more “dynamic” perspective (this underlines the more “humanist” point of view adopted in semiotics)” (Greimas and Courtés 1979, p.256).

Renunciation

“Located at the figurative level, **renunciation** characterizes the position of the subject of an utterance of state when it deprives itself of the object of value. It corresponds therefore to the reflexive disjunction of the object of value, effected at any moment whatsoever of the narrative trajectory. With dispossession, renunciation is one of the two forms of privation which can be considered, by virtue of the consequence, as sub-components of the test” (Greimas and Courtés 1979, p.262).

Samatha-vispasnya

“The practice of recognizing emptiness in every moment is known as the practice of mindfulness/awareness or samatha-vispasnya. Essentially a radical not-doing, it is traditionally understood as a universal practice, but despite having been refined and explored for 2500 years by over half the world, it was never discovered independently in the West. Instead of a space for the human in the analyst’s studio required by psychoanalysis, samatha-vipasnya creates the space through non-action, which includes nonresponse to language” (Varela 1992, p.66).

Sanction

“1. **Sanction** is a figure of discourse, correlative to manipulation, which, when inserted into the narrative schema, occupies a place in both the pragmatic and cognitive dimensions. Inasmuch as sanction is exercised by the final sender, sanction presupposes that this sender has an absolute competence. 2. **Pragmatic sanction** is an epistemic judgment, passed by the judge-Sender, concerning the conformity of the behavior and, more precisely, of the narrative program of the performing subject. It is made with respect to the axiological system (justice, ‘good manners’, esthetics, etc.), implicit or explicit, such as it was actualized at least in the initial contract. From the point of view of the subject-Receiver, pragmatic sanction corresponds to retribution. As such, it is the result of another function in the structure of exchange: it is the counterpart called for by the performance carried out by the subject conforming to its contractual obligations. This compensation may be positive (recompense) or negative (punishment); in the later case, depending on whether the punishment is given by an individual or social sender, negative retribution is called vengeance or justice. These different types of retribution permit the reestablishment of narrative equilibrium. 3. As a judgment concerning doing, pragmatic sanction is opposed to **cognitive sanction**, which is an epistemic judgment of the being of the subject and, more generally, of the utterances of state that it overdetermines thanks to veridictory and epistemic modalities. (Here could be place the concept of acceptability, used in generative grammar and presented as an epistemic judgment, comparable to cognitive sanction.) From the point of view of the subject-Receiver, cognitive sanction is equivalent to the recognition of the hero and, negatively, to the foiling of the villain. Recognition on the part of the Sender is the compensation resulting from the glorifying test, taken on by the subject-Receiver. 4. By transposing sanction, viewed as a narrative trajectory, to the level of social semiotic practices, we can foresee the elaboration of a **semiotics of sanction** (correlated to a semiotic of manipulation and a semiotics of action) ” (Greimas and Courtés 1979, p.267).

Semantic field

“A semantic field comprises all the meanings (semes) attached to a particular signifier in the text. The signifier ‘fame’ may thus include the meaning ‘celebrity’, ‘stardom’, ‘repute’, ‘honour’, ‘glory’ or ‘eminence’, ‘illustriousness’; the semantic field of ‘joke’ might comprise ‘witticism’ and ‘anecdote’ or ‘prank’, ‘trick’ etc. The term semantic field is often interchangeable with that of lexical field” (Martin 1994, p.114).

Seme

“Seme commonly designates the ‘minimal unit’ of signification” (Greimas and Courtés 1979, p.278).

Semiotic object

“In the framework of epistemological reflection, **object** is the name given to that which is thought or perceived as distinct from the act of thinking (or perceiving) and from the subject who thinks (or perceives) it. This definition – which is not really a definition – suffices to say that only the relation between the knowing subject and the object of knowledge grounds them as existents and as distinct from one another. This is an attitude which seems totally in conformity with the structural approach to semiotics. It is in this sense that we speak of object language or of semiotic entity, by insisting upon the absence of any *a priori* determination of the object other than its relation to the subject. 2. Perceived in this way, the object is but a formal position; it is knowable only by its determinations which are, also, relational in nature. The object is constituted through the establishment of relations (a) between it and other objects; (b) between it considered as a whole and its parts; and (c) between its parts, on the one hand, and the set of relations previously established, on the other. As a result of the construction carried out by the knowing subject, the **semiotic object** is therefore reduced as L. Hjelmslev says, to “intersecting points in these networks of relations” (Greimas and Courtés 1979, p.216). There is a strong parallel between this definition of object, subject and that which is perceived or thought and the experience, experiencer and the relation between them of basic element analysis.

Semiotic square

“1. By **semiotic square** is meant the visual representation of the logical articulation of any semantic category. The elementary structure of signification, when defined – in a first step – as a relation between at least two terms, rests only on a distinction of opposition which characterizes the paradigmatic axis of language. It is, consequently, adequate for the establishment of a paradigm composed of *n* terms, but it does not thereby allow for the distinction, within this paradigm, of semantic categories founded on the isotopy (the “family relations”) of distinctive features which can be recognized therein. A typology of relations is necessary, which will make it possible to distinguish intrinsic features, those which constitute the category, from those which are foreign to it” (Greimas and Courtés 1979, p.308). For a more detailed description of the semiotic square see (Greimas and Courtés 1979, pp.308-11).

Sender

“1. The terms **sender** and **receiver** (usually written with a small first letter)-taken over from R. Jakobson’s schema of linguistic communication-designate, in their most general sense, the two actants of the communication (also called in information theory source and receptor, but in a mechanical and non-dynamic perspective). When they are viewed as logically presupposed implicit actants of every utterance, they are called enunciator and enunciate. When, by contrast, they are explicitly mentioned and are thereby recognizable in the utterance-discourse (for instance, “I”/“you”) they are called narrator and narratee. Finally, when the discourse reproduces the structure of communication by simulating it (*cf.* dialog*), they are called interlocutor and interlocutee. In these last three cases it is clear that we are dealing with an act of delegation originating from the sender and the receiver 2. Considered as narrative actants, Sender and Receiver, (in this case usually written with a capital letter) are actantial domains characterized by a relations of unilateral presupposition (between Sender as presupposed term and Receiver as presupposed term). Consequently the communication between them is asymmetric. Paradigmatically, the Sender is in a hyperonymic relation with the Receiver, while the latter is in a hyponymic position. This asymmetry is amplified in the syntagmatization of these two actants, when they appear as two subjects concerned with a single object. This is what happens, for instance, in the case of participative communication. Sender and Receiver are stable and permanent narrative actants, whatever might be the roles of communication actants that they can assume. Thus the subject-Receiver communicates, as sender, knowledge about its own performances. 3. Often posited as belonging to the transcendent universe, the Sender is the one which communicates to the subject-Receiver (belonging to the immanent universe) not only the elements of modal competence, but also the set of values at stake. The Sender receives the communication concerning the results of the subject-Receiver’s performance; it falls to the Sender to sanction this performance. From this point of view and in the framework of the narrative schema, the **manipulatory Sender** (the initial Sender) can be opposed to the **judicatory Sender** (the final Sender)” (Greimas and Courtés 1979, pp.293-294).

Sender

“The sender normally occupies the positions of mandatory sender and of sender-adjudicator. At the beginning of a narrative programme, the sender establishes a contract with the future subject and

instigates the system of values in accordance with which the subject must act. The sender here is sometimes referred to as the mandatory sender to distinguish it from the later role of sender-adjudicator. The latter is the sender who intervenes at the stage of sanction or the glorifying test. At this point the performance of the subject is being judged with regard to the original mandate [...] The roles of mandatory sender and of sender-adjudicator, however, are not always held by the same actor” (Martin and Ringham 2000, p.122).

Shamatha (Sanskrit) *shine* (Tibetan)

Meditation for stilling and calming the mind. Traditionally, a concentration technique. It is rarely practiced in its most pure, radical form. (Varela, Thompson, and Rosch 1991, p.255)

Solipsism

Solipsism is “the view or theory that self is the only object of real knowledge or the only thing really existent” (1989).

Somatisation disorder

Somatisation disorder is characterised by:

Recurrent, multiple somatic complaints for which medical attention is sought but which have no apparent physical cause are the basis for this disorder. Common complaints include headaches; fatigue; allergies; abdominal, back, and chest pains; genitourinary symptoms; gastrointestinal symptoms; symptoms suggesting a neurological disorder; and heart palpitations (Davison and Neale 1994, p.169)

Spatialization

“In the overall generative trajectory, **spatialization** appears as one of the components of discoursivization (*i.e.*, the putting into discourse of deeper semiotic structures). First, it comprises procedures of spatial localization, which can be interpreted as operations of disengagement and engagement, carried out by the enunciator in order to project out from itself and apply onto the utterance-discourse a more or less autonomous spatial organization that serves as a framework for the inscription of narrative programs and their concatenations. Spatialization also includes procedures for spatial programming, thanks to which a linear disposition of partial spaces (obtained through localizations) is realized; this disposition conforms with the temporal programming of the narrative programs” (Greimas and Courtés 1979, pp.306-307).

Subject

According to Martin and Ringham, “semiotics employs the term agent (or operating agent) to designate the narrative role of a **subject of doing**, that is, of a subject engaged in the carrying out of a particular narrative programme. It contrasts with the term **patient** which designates a **subject of state**” (Martin and Ringham 2000, p.23). Greimas and Courtés do not directly define agent or agency but provide the following definition of the subjects of state and doing: “consequently, there correspond to the two types of elementary utterance (the utterance of state and being, and the utterance of doing) two types of subjects: the first type consists of **subjects of state**, characterized by a relationship of junction with objects of value ... the second type consists of **subjects of doing**, defined by the relationship of transformation” (Greimas and Courtés 1979, p.321).

Syntagmatic

“When any knowable object is semiotic in character, it can be perceived either as system or as process – its two fundamental aspects. In such a case, the term **syntagmatic** is used to designate the process” (Greimas and Courtés 1979, p.327).

Temporalization

“Temporalization consists, as its name implies, in producing the meaning effect ‘temporality’ and in thus transforming a narrative organization into a ‘story’” (Greimas and Courtés 1979).

Thematization

“In discursive semantics thematization is a procedure – still relatively unexamined – which first takes over the values (of fundamental semantics) that are already actualized (in junction with subjects) by narrative semantics. It then, in a way, spreads them out, with various degrees of concentration, in the form of themes, in the narrative programs and trajectories. Thematization thus opens the way to possible figurativization of themes. Thematization may either be more focused upon the subjects, objects, or functions, or else be equally spread out over the different elements of the appropriate narrative structure” (Greimas and Courtés 1979, p.344).

Thymic

“Situated on the deep level of an utterance, the thymic category relates to the world of feeling and of emotions. It spans the notion made up by the two poles euphoria versus dysphoria and forms the basis of positive/negative evaluation. In other words it gives rise to an axiological system – a characteristic of all discourse” (Martin and Ringham 2000, p.134).

Uncertainty

“The contradictory term for certainty within the epistemic modal category, **uncertainty** is the name of the modal structure of *not-believing-to-be*” (Greimas and Courtés 1979, p.355).

Veridiction

“The integration of the set of problems concerning truth within the uttered discourse can be interpreted first of all as the inscribing (and the reading) of the marks of veridiction, thanks to which the utterance-discourse shows itself as true or false, lie or secret” (Greimas and Courtés 1979, p.367).

Vipassana (Pali)

The meditation technique practiced today in the Theravada tradition of Buddhism. Its purpose is both to calm the mind and arouse insight. The general technique is for the mind to remain mindfully with its object, whatever that object may be. There are many specific techniques. (Varela, Thompson, and Rosch 1991, p.255)

Virtualization

“1. In the framework of the modes of semiotic existence, the *virtual/actual* category permits a characterization of the relation between system and process, between language and speech. Contrary to actual existence, which belongs to the syntagmatic axis of language, **virtual existence** characterizes the paradigmatic axis: it is an existence “in absentia.” 2. Narrative semiotics has been led to substitute the ternary articulation *virtualization/actualization/realization* for the couple *virtualization/actualization*. From this point of view, **virtualization** corresponds to the act of positing subjects and objects prior to any junction (or, inversely, of purely and simply suppressing this relation). In the framework solely of the utterances of state, it is the role of the function to operate their actualization by disjunction and their realization by conjunction” (Greimas and Courtés 1979, p.371).

Vispashyana (Sanskrit) lhagthong (Tibetan)

Insight. The term is used in at least two major senses: 1. Specific techniques used within meditation for examining the calmed mind to obtain insight into its nature. ... 2. The panoramic awareness in meditation or daily life that enables the practitioner to see with a sense of mature wisdom whatever is occurring. (Varela, Thompson, and Rosch 1991, p.255)

Wanting

“1. **Wanting** is the name chosen to designate one of the predicates of the modal utterance that governs either an utterance of doing or an utterance of state. ... 2. According to the type of utterance it governs, the modal utterance of *wanting* is a constituent of two modal structures that can be designated, for short, as *wanting-to-do* and *wanting-to-be*” (Greimas and Courtés 1979, p.372).

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